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ABSTRACT

Ten issues of the 1997 newsletter of TASH comprise this document. An issue typically contains news items, a column by the organization's executive director, reports from special interest groups, legislative testimony, conference information, and several major articles, such as the following: "Multicultural Perspectives: Excerpts from Opening Plenary Session Remarks of Beth Henry"; "Celebration of Twenty Years of Circle of Friends" (Marsha Forest and others); "A Reflection of Parent Empowerment" (M. Carmen S. Ramirez); "School Inclusion and Social Relationships in Italy" (Carol Berrigan and Dennis Taylor); "India's Story: How IDEA Protected Her Rights" (Barbara and M. Wayne Dyer); "Frequently Asked Questions about Part B of the Individuals with Disabilities Education Act"; "Isn't It about Achieving Balance? Participation in Content-Area Classes and Community-Based Instruction in Secondary Schools" (John McDonnell); "Inclusion in the Public Schools: Strategies for Parents" (Mark Partin); "What We Want: By Self-Advocates Becoming Empowered, the New Self-Advocacy Organization" (Rick Betts and others); "The Underachievement of Supported Employment: A Call for Reinvestment" (David Mank); "Positive Behavioral Support with Families" (Joseph M. Lucyshyn and others); "Take Risks, Ride the River" (Barbara Buswell); "No Time for Silence" (Douglas Biklen); "Blending Best Practices for Young Children: Inclusive Early Childhood Programs" (Marquita Grenot-Scheyer and others); "One Community's Efforts To Promote Child Care Inclusion" (Dianne Apter and Pam Walker); "Dave Hingsburger's Hot Fudge Sunday'" (Dave Hingsburger); "Practical and Useful Tools for Change" (Marsha Forest and Jack Pearpoint); "Standing in Support, Not Control: Training toward Self-Reliance, Inc." (Pam Walker); "Conversion from Facility-Based to Community-Based Employment Supports: Preliminary Results of a National Study" (Pat Rogan and others); "Why Are We Reinstitutionalizing People during the Day?" (Leslie L. Wilson); "People First Members Work To Tear Down Institution Walls"; "Supported Employment: Ten Years After" (Michael West and others); "Children with Disabilities in Youth Sports" (Cynthia Burkhour); "Inclusion as a Force for School Renewal" (John O'Brien and Connie Lyle O'Brien); "Solution Circle: Getting Unstuck: A Creative

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Problem Solving Tool" (Jack Pearpoint and Marsha Forest); "Gay Man with Disabilities Troubled by Life's Barriers" (Anne Harris); "Inclusion and the 1997 IDEA Amendments" (Frank Laski); "Self-Determination and the Search for Community" (Dennis Harkins); "Self-Determination: Transferring Agency Control by Re-Thinking Its Role" (James Dehem and Lisa Chapman); "Self-Determination--A Family Perspective" (Cameron Tease); "Self-Advocates Discuss What Self-Determination Has Meant to Them". (DB)

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Tash Newsletter

Volume 23

Issue Numbers 1-10 1997

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Newsletter

VOLUME 23 ISSUE NUMBER 1 [illegible]

NOT DEAD YET
Your pity is Killing Me
NOT DEAD
WE'RE NOT BETTER OF DEAD
MARYLAND

IMPORTANT!
Dated Material Inside!
1997 Call For Presentations

INSIDE: School Inclusion in Italy,
Multicultural Perspectives and Assisted Suicide Debate

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This is a poem that Vicky Medina wrote to her son, Fernie. She wanted to share it with all the parents and caregivers dedicated to caring for children with special needs, so they never feel alone.

Because of my great love for you, I accept my great challenge in my life, as you have cerebral palsy, mental retardation, autism and epilepsy. Knowing that people will see you as a child without hearing or sight and born to merely die, I want you to know that you are my treasure in life. You are gracious, fragile, beautiful, difficult, slow and have gifts and abilities.

Through your love, I understand that God loves me as He gave me a son who is different, as we all are in this world. In times past, I recall painfully asking myself it you could hear me, if you could feel the warmth of my love as I held you, as I rocked you, as I sang to you and talked to you. I find that as time goes on and as you grow that the warmth of my love has given your small, frail body and hand the strength to hold yourself up and walk with the use of a walker.

I learn with you to respect your need to take risks. To take risks just like every other child—the risk of falling and picking yourself up again and learning to walk. My heart breaks as I see you fall and try again. My great love for you and belief in you gives me the confidence in my constant challenge to help the world see you, my son, as more than an invalid, defenseless, silent child.

I want you to cry and laugh and say "Mom" and with these gestures begin to communicate. With you I have learned that love is not easy and miracles demand great effort. With time and through total integration into the community, I see you face life with agility and without fear. I believe I can build a bridge across a river as strongly as I believe that I will see you moving with great ease and freedom. Water flows through your fingers. I hear your voice as you say MOMMY!

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Este es un poema que Vicky Medina escribio a su hijo, Fernie. Ella quiso compartirlo con todos aquellos dedicados al cuidado de niños diferentes para que nunca se sientan tan sotos.

Por el amor que por ti siento, acepto el reto en mi vida pues tú tienes paralisis cerebral, retraso mental, autismo y epilepcia. Aún sabiendo que la gente te mirara como un niño solo nacido para morir. Quiero que sepas tú hijo mio, que eres para mi un trofeo a la vida. Tú eres gracioso, fragil, hermoso, dificil, lento, y con algún talento y alguna abildad. Atravez de tu amor entiendo que Dios me ama tanto que mi hijo es diferente como todos somos diferentes en el mundo. Recuerdo el tiempo pasado con el sufrimiento que sentia preguntandome a mi misma si me escuchabas, si sentirias el calor de mi amor teniendote entre mis brazos meciendote, cantandote, durmiendote y platicandotel. Me doy cuenta que el paso del tiempo al estar creciendo, es el calor de mi amor el que te ha dado la fortaleza en tu pequeño y espigado cuerpo que te ayuda a ponerte de pie sosteniendote con tus manitas sobre tu andador para poder caminar. Aprendiendo contigo a respetarte tu gran necesidad de riesgo al igual que cualquier niño, el riesgo de caer y levantarse para aprender a caminar sintiendo mi Sorazón quebrar al verte caer y nuevamente volverlo a intentar Mi amor por ti y el creer ,en ti me da la seguridad que con mi lucha continua conseguiré que el mundo no te vea hijo mio solo como un desvalido, indefenso, silencioso niño. Quiero que llores, que rias y sonrias y me digas "Mama". Y de esa forma empezar tu nuevo comunicar. Contigo he aprendido que el amor nunca viene facil y que los-milagros exigen gran esfuerzo y que atravez del tiempo con tu integración total en tu rostro una gran felicidad moviendose libre mente ... en una corriente continua atravez de tus manos. Escuchando tu voz atravez de tus labios diciendo: MAMA!

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BY FRANK LASKI

As we usher in a New Year, I am full of thanks for the opportunity to serve and work with TASH members across the continent during the most eventful, testing, and promising time in the movement for the fulfillment of the rights of persons with disabilities and their families. It is a time when the disability rights movement is the most vital and most universally relevant civil rights movement in our nation. It is a time when TASH is well equipped to extend its strong traditions and contribute in small but important ways to the vitality of the movement. It is a time for unrestrained optimism. A time to say, "1997 will be a good year."

How could it be less? Just a short year ago, the new Speaker of the House and a phalanx of Republican governors stood ready to gut basic health, education, and community living supports and divide the spoils in blocks to the states. Now with education intact, Medicaid cuts averted, and an election that was bumbling for all office holders, it was not they but the masses of people with disabilities, their families and allies led by Justin Dart, Mark White and the rest, who could declare *Veni Vidi Vici*. The test of this year's past was a test that strengthened all who participated. We can now see that in 1997:

- Rather than compromising for crumbs, we can begin to renew IDEA by enforcing its substantive guarantees, and extending the original vision of the right to education all children.
- Rather than fighting for a Medicaid safety net that finances facilities, we can begin to work with ADAPT to redirect federal long-term care dollars through a new Community Attendant Services Act.
- Rather than debate "full inclusion" within the profession and in public, we can devote our energies to its effective implementation at all levels of schooling.

All who met in New Orleans were encouraged and inspired by the remarkable coherence of the message of Sandra Jensen, Emma Van Der Klift, Norm Kunc, Beth Harry, Justin Dart, and Thomas Gilhool. It was a message of revolution in progress, substantial achievement by and for some, promises yet to be met for many; a message of the strength that comes from mutual respect and support in times of crisis and over the long term.

"It is a time when the disability rights movement is the most vital and most universally relevant civil rights movement in our nation."

The message of our conference and, indeed, the mission of TASH, can be recounted in many individual stories. Sandra Jensen's story is one. Mark Hartmann's story is another.

In the November 1994 *Newsletter* we reported on a serious setback for 9 year-old Mark Hartmann and his family. Mark, who as a first grader was enrolled full time in a regular classroom in Butterfield Elementary School in Lombard, Illinois, had the bad luck to move to Loudoun County in Northern Virginia. Mark's parents were led to believe that regular schooling with classroom supports would be available there. In fact, Loudoun County was not prepared or committed to support Mark in regular class and recommended instead a self-contained classroom for autistic children. Over Mark's parents' objections, the Virginia hearing officer approved the separate class placement, finding that Mark could not benefit in the regular classroom, and that "mainstreaming" him in art, music, gym and recess was enough.

The Virginia decision was, of course, devastating for Mark and his family, and particularly troubling because the hearing officer completely discounted Mark's successful experiences in inclusive classes in Illinois. Mark's parents persisted, moved Mark out of the Loudoun County school system and appealed to the federal court in Alexandria, Virginia.

In late November, three long years after Mark moved to Loudoun County, Federal District Court Judge Leonice Brinkema ruled that the school district's segregated placement plan "violated its duty under IDEA to educate Mark to the maximum extent appropriate with children who are not disabled."

In many ways the story of Mark, now 11, is similar to the story of Rachel Holland, Rafael Oberti, and others: dedicated parents, informed advocates, a resistant school board (Loudoun County will appeal), and the substantial financial and emotional costs of a process that can overwhelm all but the most persistent and creative families. However, Mark's case is different and the ruling of Judge Brinkema is a new turning point. In Mark's case, there was little argument about the law, about what IDEA requires or about the legal presumption for regular class inclusion. In 1996 all of that was clear to the school district and the hearing officer. The issue in this case was whether school districts can avoid their duty to include by not providing their regular class teachers and staff with the training and support that will make effective regular class placement possible.

Specifically, the federal court ruled Loudoun County's "efforts to include Mark were inadequate because the Board failed to follow the advice of properly qualified experts like [Jamie] Ruppman and [Mary] Kearney, and instead placed staff on the IEP team who had inadequate training and experience, thereby dooming their inclusion effort to failure."

The court's proper focus on the school's duty to build and maintain the capacity to include children like Mark, particularly the duty to employ well-trained and experienced staff, was the result of great efforts on the part of Roxanna and Joseph Hartmann, their attorney Gerald Rugel, their experts Jamie Ruppman, Gail Mayfield, Pat Schwartz, Mark's teachers Beverly Stranger, Cathy Thornton, and the Illinois team in Butterfield Elementary that started it all.

As we enter the New Year, there are still too many Loudoun Counties, too many state hearing officers who want children to prove they deserve to be included, and too many state departments of education that tolerate important educational decisions made and implemented by untrained, unqualified people. But not for long. Because the story of Mark Hartmann is just one of many in the growing TASH network and because the respect that Mark has earned in his first five years of schooling and the support he and his family have mobilized in Virginia serve to focus and strengthen us all, 1997 will be a good year.

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TASH (The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

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Building communities in which no one is segregated and everyone belongs;

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Forging new alliances that embrace diversity;

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Advocating for opportunities and rights;

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Eradicating injustices and inequities;

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Supporting research;

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Promoting inclusive education; Disseminating knowledge and information;

~

Supporting progressive legislation and litigation; and

~

Promoting excellence in services

EDITOR'S NOTES

This month's issue of the *Newsletter* covers several distinct, yet related areas of interest for disability advocates. As an organization of, by, and for persons with disabilities, TASH advocates for inclusion of all people in every area of life. Sadly, the opportunity to exercise free will and choice is a right enjoyed by too few. Obstacles which stand in the way of quality of life for one group have the potential to compromise the quality of life for others. We must be ever mindful that the values we hold dear cut across cultural and ethnic lines, as well.

Our indefatigable efforts to ensure justice and promote equity for all were again in evidence when, anchored by members of the group Not Dead Yet, we rallied in front of the United States Supreme Court to collectively voice our opposition to the possible legalization of physician-assisted suicide. Beginning on page 5, Nancy Weiss gives us a powerful perspective on the decisions persons with disabilities have been forced to make regarding suicide when few, if any, other options appear to be available. Stalwart TASH allies Justin Dart, Mike Auberger, Nancy Ward and Lucy Gwin spoke compellingly against the legalization of physician-assisted suicide during the January 8th rally. Some of Mike's and Nancy's rally day remarks are recounted on pages 7 and 8.

Beth Harry gives us pause to consider the meanings and interpretations of words and actions when persons with diverse value systems communicate (page 9). Both English and Spanish language versions of Carmen Ramirez's article on becoming an empowered parent advocate are featured on pages 14-15. Carol Berrigan and Dennis Taylor of the Center on Human Policy describe inclusive education and social relationships in Italy (page 21). And the origins and work of the TASH Multicultural Interest & Action Group are detailed on page 27.

Justin Dart's stirring keynote luncheon address during the 1996 TASH conference challenged each of us to join the "revolution of empowerment" (page 16). This issue also features the "Call for Presentations" for the 1997 TASH annual conference in Boston. The deadline for

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WHOM DO I CONTACT??

- **For issues of policy, chapter or committee support or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail nweiss@tash.org
- **For information on the conference, including presenter information, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For information on regional workshops, information and referral, technical assistance, or government affairs, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:mroth@tash.org
- **For information on membership, publication/video sales, reprints, and advertising, call:** Priscilla Newton, Director of Member Services, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the newsletter or to make a submission, call:** Priscilla Newton at (410) 828-TASH, Ext. 102.
- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230.

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FROM THE EXECUTIVE DIRECTOR

BY NANCY WEISS

This issue of the *Newsletter* is about multicultural issues; it is about understanding the variety of beliefs, values, concerns and priorities that are to some extent, products of people's cultural experiences. In her article, beginning on page 8 of this issue, Beth Harry provides thought provoking descriptions of situations in which people's actions might have been perceived as strange or uncaring if the meaning of those actions was not understood within the context of cultural differences.

Just as cultural gaps exist among people with different ancestry, a major cultural gap often exists between the disability community and others who are not disabled or who have little exposure to the concerns of people with disabilities. An excellent example of this gap is the current effort on the part of people with disabilities and advocates to fight the Supreme Court's approval of physician-assisted suicide.

Most able-bodied people I have spoken with on the issue of assisted suicide do not seem to understand what all the controversy is about. They seem certain that if they were terminally ill, in pain, and had no hope of recovery, they would want the option of ending their lives in a painless, dignified way. They argue that if legalized physician-assisted suicide would only offer an option. Surely, they reason, safeguards would be in place to assure that it is an option that is exercised only at the clear direction of the individual with the terminal illness. People with disabilities and their advocates, however, see the potential outcomes of a Supreme Court decision in favor of legalization far differently.

I think that even the strongest opponents of the practice would agree that there are individual circumstances in which the ability to elect suicide with a physician's assistance would be a humane alternative to intolerable suffering. However, the potential for people with disabilities and other devalued populations to become victim to such a "right" is very real. It is this very plausible fear that creates the impetus for national campaigns against the approval of physician-assisted suicide. A group called Not Dead Yet has formed to take the lead in the fight against assisted suicide. Not Dead Yet filed a powerful amicus brief with the Supreme Court on this issue. TASH has registered its formal support for their brief.

As you'll see in the cover photos, and those that follow, TASH recently participated in a rally at the Supreme Court in Washington to protest the legalization of assisted suicide. Marcie Roth, TASH's Director of Governmental Affairs, was very instrumental in organizing the event, along with members of Not Dead Yet and the staff of *Mouth*. The January 8th rally received good coverage on most major networks and front page stories in USA Today and most major newspapers. People with disabilities, their family members and advocates came out in force for the rally, united against the Supreme Court's approval of physician-assisted suicide.

One of the most readable and compelling arguments against assisted suicide is in Joseph P. Shapiro's history of the disability rights movement, No Pity (Times Books, 1993 - a book that no one in the disability movement should miss). Chapter nine tells the story of Larry James McAfee. McAfee was a young man from Georgia who became quadriplegic as a result of a motorcycle accident. He used a respirator. Due to the vagaries of Medicaid and Medicare funding, McAfee was shuttled among the intensive care unit of a hospital and bad nursing homes. Because Georgia paid the same rate to nursing homes whether the individual used a respirator or not, most nursing homes wouldn't accept him. He had no prospects for a job, a place of his own, or a life of his own. McAfee said, "Every day when I wake up there is nothing to look forward to. People say, 'You're using my taxes. You don't deserve to be here'. You just reach a point where you can't take it anymore."

McAfee had been close to receiving a degree in engineering when he was injured. Now he used those skills to design a mechanism with which he could commit suicide. After a complicated series of legal hearings, the decision was made to allow McAfee to kill himself. In the meantime, people heard about McAfee. Russ Fine, the Director of the Injury Prevention Research Center at he University of Alabama let McAfee know that he supported his right to commit suicide, but wanted to make sure he knew his options first. He said, "... we have the technology literally to resurrect the near-dead but not the additional components to address quality of life." With Fine's involvement as friend and advocate and through the contacts he eventually made with others, McAfee's life began to improve. Disability advocates took up the fight. He received an environmental control system that allowed him to use his telephone and TV and a computer that was voice activated. He was able to use the computer to do the kind of work he had been doing before his accident. He finally moved into a home of his own with personal assistance. He said he was happy to be alive and that he was "living a good life". If it weren't for all the bureaucracy that entangled him, McAfee might have taken his life long before the opportunity to have a life was made available to him.

McAfee's story illustrates one of the major failings of the argument for assisted suicide. People with disabilities don't want to be assisted to die; they want assistance to achieve a better quality of life. When people with disabilities do elect suicide it is probably far more likely due to the limits imposed on them by short-sighted health care and support systems than those imposed on them by their particular disability or medical condition. People in this country do not have a legal right to basic health care, home supports, or humane living conditions. It would be ironic if the first such right guaranteed by the Federal legislation was the right to be assisted to die.

A determination that will need to be made should assisted suicide be legalized is the question of who is terminally ill. One of the cases heard by the Supreme Court stated that, "According to the model

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From The Executive Director

Continued from page 5

act, a patient is in a terminal condition if the medical condition is incurable and irreversible" (Judge Stephen Reinhardt) Wouldn't almost all people with disabilities potentially be included under such a definition? The truth is, the vast majority of people who actually are terminally ill want to be made comfortable, have the companionship of family and friends around them, have their pain adequately managed, and be in their own home or the environment that can best meet their needs while being as much like a home as possible. Terminally ill people whose needs are well met, don't typically want to hasten their death.

Issues around managed care further complicate the discussion. Paul Longmore, a history professor at San Francisco State University cautions, "There is tremendous danger in allowing physician-assisted suicide, given the fact that there is already a significant movement to ration health care. It is worthwhile considering where concerns over rights will end when doctors and hospitals are under enormous pressure to reduce costs." In a publication by The National Catholic Office for Persons with Disabilities and the Knights of Columbus, they caution against legalizing assisted suicide. They state, a "rule in favor of assisted suicide would pour into the Constitution a poisonous concoction of warm-hearted, misguided pity and cold-hearted utilitarianism ... Who stands to benefit most from a constitutional policy by which the right to live of vulnerable persons is reduced to an alienable interest? Is it the person with a terminal condition bent on suicide ... or is it a cost-conscious society seeking more ways to ration its generosity?"

Carol Cleigh, one of the Rally Day organizers

It is reasonable to assume that if assisted suicide were made legal, doctors would be far more likely to discuss it as an option with someone whose life, in their eyes, was not worth living. Doctors, along with the rest of society, routinely underestimate the quality of life of people with disabilities when compared with those people's own assessments. It is easy to look in from outside and glibly decide that if "that were you" you wouldn't want to live. The view from the inside is often very different. Mark O'Brien, a correspondent for the Pacific News Service expresses the feelings of many people with disabilities when he says about his own life, "It is tempting to pity a man in an iron lung. But pity has become a lethal weapon ... people have said, 'That poor thing ... how he must suffer! He's terminally ill, you know.' I'm not 'suffering', 'terminal' or even 'ill'. Don't waste your pity on me. *I want to live.*"

Even the American Medical Association recognizes the dangers inherent in giving physicians the right to assist people to end their lives. Their position statement says, "Defeat of physician-assisted suicide initiatives undoubtedly will be regarded as a hardship by certain terminally ill patients ... but there is an overriding public interest in protecting vulnerable citizens from the irreparable finality of death ... Will we become so numb to the practice that we will not find it objectionable to perform euthanasia on patients who do not want to be euthanized?" "Although for some patients it might appear compassionate to hasten death, institutionalizing physician-assisted suicide as a medical treatment would put many more patients at serious risk for unwanted and unnecessary death," the AMA's court brief says.

The AMA goes on to caution that although assisted suicide bills are written to appear to offer a compassionate alternative, the experience of doctors in the Netherlands, where physician-assisted suicide has been legal for some years, proves otherwise. Physicians in the Netherlands have learned that a prescription for a lethal dose of medication does not always have the desired result of a quick and peaceful death. In the Netherlands, approximately one quarter of the individuals who take what are intended to be lethal drug overdoses, linger for up to four days. Often death is not ensured until a lethal injection is administered. Legalizing physician-assisted suicide opens the door to the consideration of a range of practices, all of which will endanger people who some view as a burden on society.

The first step along the slippery slope toward assisted suicide occurred in 1990 with the passage of The Patient's Self -

continued on page 7

C. Everett Coop, former Surgeon General of the United States

The singing group, Spectrum.

From The Executive Director

Continued from page 6

Determination Act which requires all hospitals participating in Medicare or Medicaid to explain to inpatients that they can choose to refuse treatment and can refuse resuscitation should it be needed. A few years ago *Mouth* published a report about a young woman with a disability who came to a hospital emergency room with a severe asthma attack. As she fought for breath, hospital admissions people diligently explained that she had the right to refuse treatment. She finally forced the hospital social worker to call a doctor. The social worker's parting words were , "It's not too late. Information on the right to die is on the hospital TV channel twenty-four hours a day! You can watch it in your room!"

Prior to surgery in 1995, *Mouth* reporter Joe Ehman had to fight off a brigade of hospital, county, and home-health social workers who insisted that he sign Do Not Resuscitate Orders. As Ehman told them, "I'm only thirty years old! I don't want to die!" Over the past few months, guidelines on assisted-suicide have been developed by the Bay Area Network of Ethics Committees. There is agreement, however, that even the best guidelines will not protect people with disabilities from becoming the target of the assisted suicide "choice".

The threat to people with disabilities is real. Join the fight against physician assisted suicide. Write personal letters to the Justices of the Supreme Court (see information, below). If you'd like more information on how you can work against the legalization of assisted suicide, contact Not Dead Yet at 716-271-4231 or fax a request to 716-442-2916. To assure regular updates on this and other issues related to disability rights, consider a subscription to *Mouth* Magazine. They can be reached at 61 Brighton Street Rochester, NY 14607-2656. Or fax them at 716-442-2916.

Letters to the Supreme Court Justices can be sent to: The U.S. Supreme Court, 1 First Street, NE, Washington, DC 20543

Letters should be sent to the individual justices as listed below: Chief Justice Rehnquist, Justice Breyer Justice Ginsburg, Justice Kennedy, Justice O'Conner, Justice Scalia, Justice Souter, Justice Stevens, Justice Thomas.

Mike Auberger

Among the notable speakers at the January 8th "Not Dead Yet" Rally in front of the Supreme Court were Mike Auberger of ADAPT and Nancy Ward of People First of Nebraska. Excerpts from the remarks made by Mike and Nancy follow.

MIKE AUBERGER, ADAPT:

Today, we are here because the Government of the United States has failed to protect the rights of people with disabilities to life and liberty. The United States Government has sanctioned the incarceration of people with disabilities against their will in nursing homes and institutions. The United States Government has systematically denied people with disabilities the right to live in the community. The United States Government has routinely deprived people with disabilities services that would assist them to live independently in the community. The United States Government has conspired with the nursing home industry to prevent America's largest minority – people with disabilities – choice.

As we come to the close of the 20th century and as we begin a new millennium, people with disabilities still do not have real community options, real choice. As long as people with disabilities are refused services, education, housing, and viewed as a burden, people with disabilities will decide that the only option is to end their meager existence.

Justin Dart

Today, the highest court in the land will hear a case that will set a precedent that will stand for years to come. The United States Government would say that this case is about assisted suicide. The people involved in this case would say that this case is about the right to die. The public would say that this case is about the right to die. I say they are all wrong. I say that this case is not about assisted suicide. This case is not about the right to die. This case is about people with disabilities. I say that this case is about the right to murder people with disabilities. I say that this case is really about an easy way out for the United States Government.

This case exists for one reason and one reason only: The United States Government has abandoned people with disabilities. People with disabilities may have civil rights, but they do not have the right to: live in the community; the right to services; and the right to choice. Without the right to live in the community, without services, and without choice, people with disabilities will continue to choose to end their lives.

This is not a new issue. This issue has haunted people with disabilities since the beginning of time. Names like Bouvia, McAfee, and Berkstead come to serve as a remainder of our history. Those are the names of only three people with disabilities who had only one choice. Because they had no real choice, they sought and obtained from our justice system the right to die. An odd name for a system that will permit you to die, but will not permit you to live – only merely exist. People with disabilities all too often have made the same choice as Bouvia and others.

As long as people with disabilities are denied choice by our government, as long as our government incarcerates people with disabilities, as long as people with disabilities are denied services, and as long as disability is unacceptable, people

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with disabilities will choose death before existence.

Ultimately, when the United States Supreme Court hands down its final opinion on this case, it will change the course of history as well as the lives of people disabilities. If the high court decides to sanction the murder of people with disabilities the court, in its infinite wisdom, will be signing the death warrant for untold numbers of people with disabilities.

We must wage a war against a government that denies people with disabilities a place in the community of man. We must unite. We must organize. We must fight. We must demand our place in the community. We must make a place in the community for our brothers and sisters with disabilities. We must create choice. We must free our people.

NANCY WARD, People First of Nebraska:

I was born in 1950 and during the '50s children like me were labeled mentally retarded. Now my label is "learning disabled". However in the '50s there was no such thing. Many children like me were put in institutions. I was lucky and grew up with my family. I had some opportunities and have been able to do a lot with my life.

I am opposed to legalizing assisted suicide. Years ago, People First of Nebraska filed an amicus brief about the Baby Doe case, which was about a baby with Down Syndrome who was denied surgery that he needed to live. He starved to death. That was my first exposure to this issue.

Parents and professionals still make decisions for people with mental retardation and other developmental disability labels. Because I have seen it, I believe that people with these labels can make decisions and choices for ourselves. But we are not given the opportunity. People in general don't believe that we can make our own decisions and because of that, they don't see us as having any value. If they can't see us as having any value, why would they give us the opportunity to grow and have any self-worth? If we get sick and assisted suicide is legal, it would be too easy for them to decide to help us to die. We wouldn't be seen as having any quality of life, anyway.

I want to give an example. I have a friend, Sally, who had cerebral palsy and could not speak well enough for people to understand her. Almost everyone assumed that she didn't understand anything, that she couldn't think. They couldn't understand why I would want to be her friend because they couldn't see that it was a two-way street. They couldn't see that I was getting something from the friendship, also. Sally is no longer alive, but when she was, she was the kind of person people would assume had no quality of life. I know that because I saw how people treated her. I am really afraid for all the Sallies of the world if assisted suicide is made legal.

To me, people with disabilities have a lot of value. They are valuable to themselves and to the other people in society. A lot of people with disabilities are my friends, and I see them as my friends as opposed to someone you have to feel sorry for. Having a disability myself has helped me to understand life, and to learn to speak out for myself. Without my disability, I think I would have had a much less fulfilled life because I wouldn't have learned to feel life the way I do. I have felt the prejudice that people have, and I have had to learn to deal with that. I have also been able to see people develop their self-advocacy skills and grow. Without my disability, my life would have been a lot shallower because I wouldn't have had the chance to experience all these things.

Many of us may need support to have good lives, but we should get that support instead of being offered the chance to be assisted to die. All we are asking for is to be treated the same as everybody else, have friends, a job, go to school, have a family – to have the things in life that anyone would want. Don't offer us the chance to die instead of these things. Don't legalize assisted suicide.

EDITOR'S NOTES

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receipt of proposals is **March 31st**. Additional information and the application form can be found on pages 25 and 26.

Finally, enter to become a part of the first ever TASH Photo Contest! Selected photos will appear in the 1998 "We the People, All the People" calendar. Details on how to enter can be found on page 29.

And thanks of those of you who've already mailed or faxed back the results of the mailing survey included in the December issue. Some of the responses so far: it took 6 days to receive the Newsletter in Morrison, Illinois, 7 days to reach both West Bend, Wisconsin and Washington, D.C. (right down the road from us!), 8 days to arrive in St. George, Utah, 11 days to reach Irvine, California, and the Newsletter was received in Dover, New Hampshire in 12 days. Please continue to send in your surveys; they're useful both to postal officials and to us.

— Priscilla Newton, Editor

1996 TASH Annual Conference

Excerpts from Opening Plenary Session Remarks of Beth Harry

> **"When I think about families that we work with who come from different backgrounds, have different experiences, and hold different values, I realize how deeply embedded their beliefs are, just as our beliefs are so deeply embedded that when we talk about them, we don't stop to recognize what they represent."**

We are about very serious business in TASH. The point that Frank (Laski) made about values as a basis at TASH and the acknowledgment that our research reflects and is charged by our values is a very important statement. It's a different statement for the research community, which taught us for years that research was value-free, neutral and objective. We know that is not true because we approach the questions we want to ask, and we frame the questions we are going to ask, based on things we are interested in and things we believe in. I've done that myself, just as have most people who have worked with or for TASH.

My own work and research has been very focused on parents and families from diverse cultures. I use that term very cautiously because we sort of throw it around these days as if we know what it means. Diverse simply means there's a variety. What I want to emphasize today is the very broad variety in values. That's what we are about in TASH — values. I think the fact that we are so committed to a certain value frame can make it at once an advantage. However, once we have that advantage of caring about people, of coming from a certain type of value position, it can also make it difficult for us to work with people who come from very different value positions.

That's the kind of communication issue I want to talk about this morning. The research that I and several other people have been doing for many years now has looked at the kind of cultural issues that undermine the communication we try to establish with families from a variety of cultural backgrounds. As we talk about things, we sometimes assume that everybody with whom we speak shares the same interpretation.

In the research that has been done on families with diverse backgrounds, we see that certain of the cornerstones of American social philosophy are, in fact, alien to many of the families we work with. I don't mean just families from foreign cultures. Of course, the difference in nationality has a very big impact. However, I'm talking about people who live within the United States and people who are Americans but are from sections of a society that does not necessarily hold the values of mainstream society.

■ One very common cornerstone which represents a point of difficulty for us is what I term economic productivity. I was very interested in Norm's (Kunc) earlier statement about the need for us to expect a contribution from people with disabilities. We would all value that. However, what is the nature of the contribution? What does it have to be? In American society, we are so given to the belief that productivity means economic productivity. We have used that to define, to a great extent, our expectations for people with disabilities. I'm going to quote a bit from our colleague, Phil Ferguson, in his book "Abandoned to Their Fate."

Phil pointed out that the moral, esthetic and economic judgments contributed to attitudes toward the mentally retarded. He was looking at historical development here. He pointed out, however, that moral and esthetic judgments were the predominant concerns in decisions to institutionalize people with severe retardation. From that population, then, the economic principle became important once people were inside of an institution. Because to become economically productive became the way to earn one's way back into society. Phil said "To put the contention negatively, one feature of the emerging therapeutic perspective was the official de-emphasis of ethical and esthetic judgment and the emphasis of economic and scientific criteria."

From this perspective, the Director of the Rome State School, Bernsteins, reform efforts developed as economically based. The question was, who could be made useful? Bernstein accepted the single standard of honor of self-support and possessive individualism that decreed personal productivity to be the badge of citizenship. He goes on to say that the essence of professional expertise and the way that Bernstein justified his value to society was through economic rehabilitation or determination that such improve-

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ment was possible. In other words, the entire issue was not that the person with retardation needs to be economically useful in order to be valued. Rather, the professional would also prove his worth by demonstrating that he could assist that person to be economically productive.

Now, as we work with families from many different cultures, we find that the notion of economic productivity as an indicator of human worth is simply not held by many people. I spoke to a young Haitian woman the other day and she said to me, "You know I work in the disability field. I'm in early intervention and I do believe in all the values that we are working for. But I have a brother who has mental retardation. He is 30 years old. He has never worked in his life. We have never wanted him to work. We have never felt that we needed him to work. We believe that he is loved and valued and happy in our home as a member of our family."

Her point was that her brother did not have to be economically productive to be valued. Her value system says that the person, regardless of whether he or she is or can be economically productive, is to be valued. That young woman is coming from a culture where she could not assume that everyone would be economically productive. There are many people in her society who do not have the opportunity to be economically productive. Also, there are many people for whom it is not expected that they need to be economically productive because their measure of a person's value is not tied to money. Now, when you go to work with a young woman like that, how do we convey to her that we respect the value position that she holds? How do we begin to collaborate with her in a way that can support her family and her brother in what they think is appropriate, while at the same time not compromising our value position?

■ A second cornerstone of U.S. social philosophy that brings us to a similar dilemma is personal choice. The notion of personal choice is very powerful. Everyone of us values it tremendously. Every person with a disability who has had the opportunity to have personal choice, and to make personal choices, values the importance of it. The fact is, we are going to encounter many families for whom personal choice is not considered one of the most important things in their value system. They will tell you that is not only true with persons with disabilities, but for everyone in their family and in their community. But why is that?

The reason is that belief in personal choice is tied to our value on individualism and our belief that the individual is the most important part of a unit. We use language like "maximize our potential and develop our individualism" to reflect that belief. However, you may find yourself working with a family where that is not true. The family's and community's belief may be that the group is more important than an individual. For us to talk about the individual's rights and the personal choice of an individual with or without a disability may not ring true for all the families with whom we work.

■ A third cornerstone we encounter a lot with the families we are working with is one that we have talked about this very morning – equity. Let us call this equitable treatment. I read some very interesting research recently by Tom Wisner who was talking about differences in sibling patterns, sibling responsibilities and cross cultural settings. Wisner did some research with a group of American families of children with disabilities and one of the things that he found was that parents were concerned about how they create equitable situations for their children. They acknowledged that because their child has a significant disability, it is hard to keep an equitable balance among the siblings because the child with the greater need gets more attention. That seems pretty normal to us. Wisner, however, pointed out that when he looked at families from different cultural backgrounds, he found a very different picture.

"Diverse simply means there's a variety."

For example, some families did not have an expectation of equitable treatment among siblings. Sibling responsibility would vary according to the chronological age. Usually there was a pattern of increased responsibility and authority within the family based on the increasing ages of the siblings. That was expected within the family. Parents of those groups that Wisner talked with did not express any discomfort with this because this was their normative pattern. In fact, it was not even expected that siblings would have the same opportunity for advancement. In many families, especially larger ones, one or two siblings might be selected as those who would find access to another level of life or another level of education.

Here, again, is an example of where we might be working with a family and our assumptions are "well, all I need to know is how does the family treat the older children and how are the other siblings treated?" Then our thought might be "this is how you're going to treat the siblings, or here's how you're going to treat the person with the disability." However, it's not that simple because that family may already have a wide range of differential treatments for siblings. When they treat the child with the disability differently, that's part of the framework from which they operate. So how do we

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work with a family in a way that conveys respect for their tradition, while at the same time trying to be true to things that we believe in?

■ The fourth cornerstone is independent living. In our society, not only do we value independence, but we have also developed certain milestones which will indicate the appropriateness of the independence a person is achieving. For example, we have developed certain age levels at which we think it appropriate for a young person to go out on a date or the age at which a young adult leaves home. For we in the mainstream of American society, our normative expectation is that the transition from family life to young adulthood will occur between 18-21. Here, again, for many families that may not be true. Some families may never expect that the person will move out of the family home, even after the young adult is married. In fact, with some families you will experience that their normative expectation for an offspring's transition to adulthood may be marriage.

I work with a Salvadorian family whose daughter is 21 now and who has cerebral palsy. Her mother says the family, of course, hopes that Serita will get married some day. There is no question for that mother, however, that Serita, as well as her other children, will not move out of the home before marriage. In fact, after some got married they remained in the family home. This was an acceptable part of the extended family structure. We might find ourselves again working with families who seem resistant to the kinds of things we think we are bringing as proof of adulthood and independence. We will continue to be puzzled at the resistance we get from those families until we stop to realize that the underlying beliefs regarding independence to people in that group could be very different from what it means to us.

And, finally, I'm going to mention a very sensitive point that has been touched on this morning. Someone told me a story recently. I didn't meet the family myself, but it is the story of a Vietnamese family who had a very young child with a severe disability. The person who was working with the family visited the home and met the grandmother. This professional was shocked and horrified by the fact that the grandmother does not speak to the child, does not look at the child, does not even acknowledge the child's presence. The professional tried to find out what this behavior was all about. Eventually, through continuing dialogue which was translated by an interpreter, the professional realized that the grandmother's point of view was that this child was, in fact, dead although that is not what she really meant. She meant that all that was left of this child was her body and the grandmother believed the child should have died earlier. Only the child's body was being kept alive and her spirit was at a different level of existence at that point in time. The grandmother believed that by keeping the body here, they were holding back the real level of life of this individual. That grandmother was grieving and her approach had nothing to do with mercy killing. It was not the sort of thing that we've been talking about here. Rather, it was a totally different concept of time, place and existence. It was, of course, a statement that's very different from our belief here in the West where we have become, I think, frightened of death. For this woman, her grandchild should have been allowed to move on to what she considered a much higher plane of existence.

So what does this mean? Do we give away our values? When we go to work with a family we have to give up on what we believe in? Does this mean that we have to be nonjudgmental? We all think of nonjudgmental as a goal. How realistic is it? I would suggest that if I meet someone who holds a radically different expectation for the life of their child with a disability than the view I hold, I am likely to recoil as I hear different statements or see lifestyles that represent something different. I'm likely to make an immediate judgment which I may never change. So how can we learn to respect people even though our judgment is not going to change?

The only thing that we may be able to realistically do is to start to cultivate a sense of the relativity of these kinds of value systems. We can start to cultivate a sharper awareness of what it is that underlies our own recommendations and our own beliefs. I need to remember that every time I talk about personal choice, it is based on a belief of individualism. Every time I talk about economic productivity, it is based on the kind of industrialized and highly developed economy that we have here in the U.S. Every time I talk about quality of life, I need to remember that my own definition of life is based on a particular perception of the relationship between body and the spirit and that when the body is alive, the person is alive. If I can remember that those deep beliefs emanate from my cultural point of view, then I think it will be easier for me to remember that what the family does and says, which looks or sounds so strange to me, is based on an underlying belief that happens to be different from my own. If we can just get to a point where we can bear in mind that the values that we so cherish are not necessarily universal (expressions may even be different from culture to culture), then I believe we can begin to do a better job.

I want to end by referring to the last statement on Emma and Norman's video: "Work with me." On behalf of all those culturally diverse families, whoever they may be, wherever they may be coming from, whose experiences, beliefs, expressions, and lifestyles may be unacceptable to us, I would like to say "Respect me and work with me."

Beth Harry is an Associate Professor in the Department of Teaching and Learning at the School of Education, University of Miami. Beth came into the field as a parent of a child with cerebral palsy. She lived in Trinidad for many years, and founded the Immortelle Center for Children. Beth holds a Ph.D. from Syracuse University and focuses her teaching and research on families of African-American and Hispanic cultures.

Celebration of Twenty Years of CIRCLE of FRIENDS

MARSHA FOREST,
JACK PEARPOINT
AND
JUDITH SNOW

A standing room only crowd gathered in the room. Chairs were arranged in a large circle. There were old friends and new gathered to celebrate the circles that have been built and have lasted over these past 20 years. It was, indeed, a cause for celebration.

Judith Snow, Marsha Forest and Jack Pearpoint had invited everyone at TASH to join this celebration. It was an inclusive and friendly gathering of about 200 people. We began with a slide show called "The Power of the Dream," featuring images of friends. Many were moved by the sequences of Judith and Jack canoeing on the Madawaska River in Ontario. The concluding slides of Ed Roberts swimming with dolphins brought tears to many eyes. It is truly the power of the dream that brought everyone to the Elmwood Room that day.

Judith dubbed her circle the "Joshua Committee" many years ago. Our task was to break down the walls of the bureaucracy as Joshua had stormed those ancient walls at Jericho. After the slide show, Judith spoke eloquently as she wheeled around the circle so she could face all those who had come together that day. She spoke of struggle, of pain, of joy and of hard work to build the circle.

Marsha followed Judith to share what she had learned and to ask for reactions from the audience to what they saw in the slide show. Emma Sullivan, Jack Pearpoint and Kenn Jupp did a colorful and beautiful graphic of the audience reactions. The common thought from most was that circles do not just happen. They are something like love that takes nurturing and care and hard work.

Jack spoke and gave a big picture of building circles in a world where war is still being waged at this very moment. He remembered the Joshua Committee and reminded us that circles are for all of us.

To end the session, we posed a question to the group. What do we need to do to assure that people do not wait for a crisis to explode before they build a circle around themselves and/or their families?

That's how the circle celebration ended. We hugged those around us and with a recording of Celine Dion's "Power of the Dream" playing in the background (the lyrics are reprinted on page 12 of this issue of the *Newsletter*), we went our own ways - following our unique paths - to celebrate and meet our personal circles.

Key reflections raised by the group included:

— Build trust. This will take time.

— Prepare people for disappointment. Not everyone will follow through.

— Look at your own circle first before you try to help others build circles.

— Do not wait for a crisis; build circles for life.

— If at first you do not succeed, try, try again. That is, be persistent.

— Tell our stories and share our dreams.

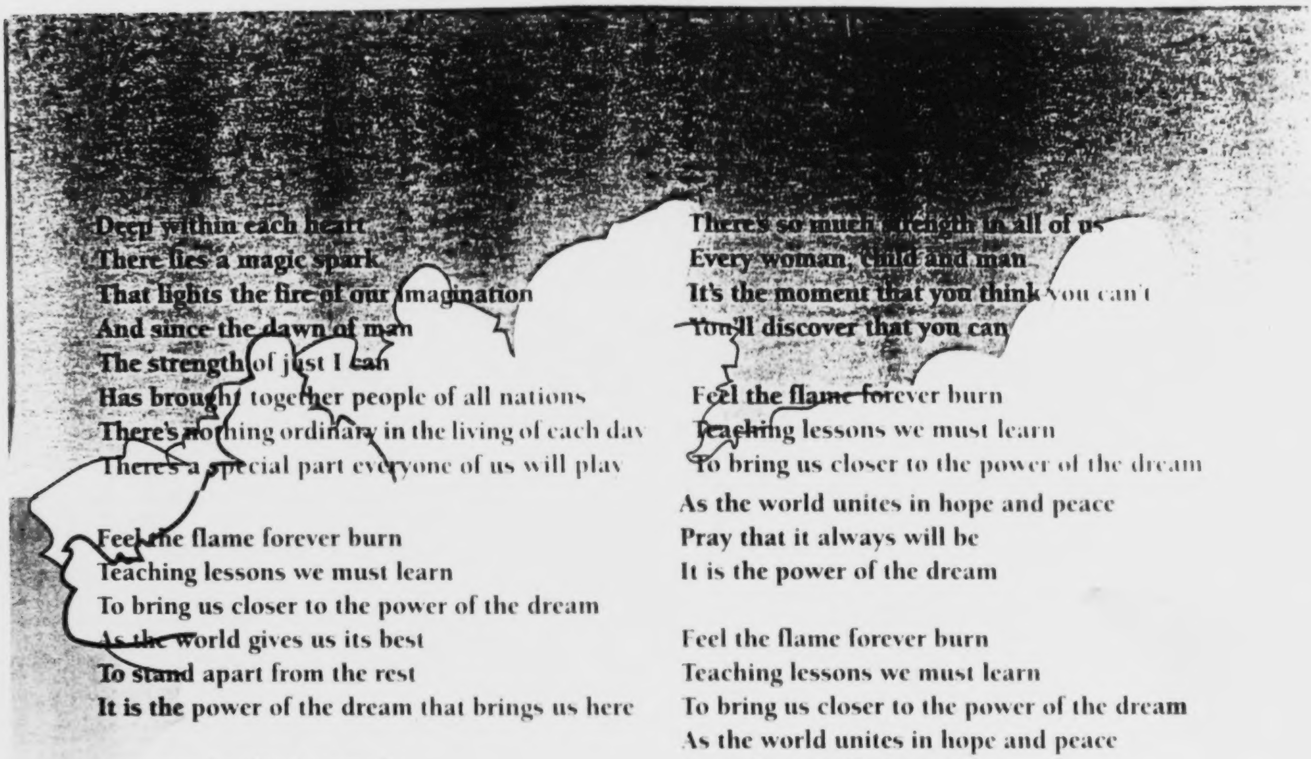
— Learn how to ASK for what you really want, not what you think you can get.

— Celebrate people for who they are.

— Challenge and stretch. Circles are not about being nice, but about helping people thrive and survive.

— And last, but not least, give big hugs!

The Power of the Dream



Deep within each heart
There lies a magic spark
That lights the fire of our imagination
And since the dawn of man
The strength of just I can
Has brought together people of all nations
There's nothing ordinary in the living of each day
There's a special part everyone of us will play

Feel the flame forever burn
Teaching lessons we must learn
To bring us closer to the power of the dream
As the world gives us its best
To stand apart from the rest
It is the power of the dream that brings us here

Your mind will take you far
The rest is just pure heart
You'll find your fate is all your own creation
And every boy and every girl
As they come into this world
They bring us the gift of hope and inspiration

Feel the flame forever burn
Teaching lessons we must learn
To bring us closer to the power of the dream
As the world unites in hope and peace
Pray that it will always be
It is the power of the dream
yeah, yeah

There's so much strength in all of us
Every woman, child and man
It's the moment that you think you can't
You'll discover that you can

Feel the flame forever burn
Teaching lessons we must learn
To bring us closer to the power of the dream
As the world unites in hope and peace
Pray that it always will be
It is the power of the dream

Feel the flame forever burn
Teaching lessons we must learn
To bring us closer to the power of the dream
As the world unites in hope and peace
Pray that it will always be
It is the power of the dream
That brings us

The power of the dream
May your days all seem
Faith in things unseen
Courage to embrace your fear
No matter where you are
Reach for your own start

To realize the power of the dream
To realize the power of the dream

Lyrics reprinted from Sony Music, Inc.'s Web Page.

Written by David Foster, Kenny "Babyface" Edmonds, and Linda Thompson
Published by Warner-Tamerlane Pub. Corp., One Four Three Music, Linda's Boys Music (BMI), Sony Songs, Inc., ECAF, Inc. (BMI)

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A Reflection of Parent Empowerment

BY M. CARMEN S. RAMIREZ

M. Carmen Ramirez is the parent of a child with a disability, a member of the TASH Board and Co-Coordinator of the Publications Interest & Action Group.

Certainly the struggle to achieve full citizenship for Americans who have been marginalized has been a tough and weary road. As the parent of a child who is challenged by disability, I have found the need to advocate for him in order to obtain the essential educational and social services which will maximize his opportunities for success in life. As a result of experiencing disenfranchisement through my ethnicity and my son's disability, I came to realize early on that if I was to empower him so that he could attain true citizenship, I needed to gain knowledge - knowledge that would hopefully translate into empowerment.

This knowledge for me, as for many other parents in my situation, meant learning about parent advocacy. It meant learning about my rights and responsibilities under the Individuals with Disabilities Education Act (IDEA), Public Law 94-142. This law, which was enacted by Congress, enabled my son to receive a "free and appropriate public education", as well as guaranteeing my rights as a parent to be involved in the decision making process of his education. I understood that if I was to truly exercise my rights as an equal partner in this process, it was essential that I knew how to implement them. Unfortunately, despite my guaranteed rights, I did not realize I was in for yet another major struggle in my life, the fight to secure an equal education for my son.

The IDEA may have secured my rights as a parent but, unfortunately, those that I was to be in "equal partnership" with refused to accept this. Regardless of these obstacles, I continued to gain knowledge and experiences so that I could advocate for my son. By so doing, I saw the desperate need to help other families in similar circumstances. I realized that many other families, especially those who did not have a command of the English language, were facing even tougher hurdles. Yet, their tenacity to overcome this barrier and others in order to help their children was to me dignifying of admiration. It was heroic.

Indeed, Angela L. Carrasquillo (1991) correctly concludes this about Latino parents regarding the education of their children: "There are indications that Hispanic parents desire closer participation in the education of their children." Ms. Carrasquillo adds that "there is a need to involve Hispanic parents in their children's education to ensure that. . . all students will learn." Ms. Carrasquillo eloquently begins the introduction of her book:

> **The course of United States history has been motivated largely by the search for a social system that would allow all individuals to advance as their abilities and efforts permit—with no barriers based on race, religion, sex, or socio-economic status. However, this is not the realistic fact for many Hispanic children and youth in the United States.**

Consequently, the same holds true for their parents. When Latino parents are not welcomed or supported in a system alien to their needs, indeed their children also suffer.

Fortunately, at the federal level the parent movement with its advocacy efforts has not fallen on deaf ears. Moreover, the struggle of Latino parents of children challenged with disabilities to be acknowledged and supported in securing our guaranteed rights under the law is now becoming a reality. As parents, we must take advantage of these opportunities and expand on them by supporting and teaching each other. For too long now, exclusion from mainstream society has prevented progress of our people. It has denied us essential participation in what is considered to be a democratic society. However, tenacious involvement in our children's education, despite the barriers we have faced, promises a path to help change this disparity. It promises a direction which may empower us to enable our children to become productive and contributing members of their communities. It's a path that tells me: *El querer es poder (To desire is to accomplish), Queramos y sigamos adelante (Let's desire and march on.), Juntos lo podemos lograr! (Together we can achieve!).*

"As a result of experiencing disenfranchisement through my ethnicity and my son's disability, I came to realize early on that if I was to empower him so that he could attain true citizenship, I needed to gain knowledge - knowledge that would hopefully translate into empowerment."

Reference:

Carrasquillo, A.L., (1991). Hispanic Children and Youth in the United States. New York: Garland Publishing, Inc.

Reflecciones De Una Madre

M. Carmen Ramirez es mama un joven retado por descapacidad, mimbra de la mesa directiva de TASH y Co-cordinadora del Groupo Integrante de Publicaciones de Interes y Accion.

Ciertamente la lucha de individuos que han sido marginalizados para obtener ciudadania verdadera ha sido un camino duro y cansado. Como madre de un niño retado por descapacidad, me he enterado de la necesidad de desempenar el papel de abogada intercesore. Pronto me di cuenta que solo de esta manera podria obtener los servicious educativos y sociales que eran esencialmente necesarios para aumentar las oportunidades de exito en la vida de mi hijo. Debido a la experiencia de ser excluida y vivir ciudadania de segunda clase a traves de mi etnicidad y el impedimento de mi hijo, llegué a comprender además que si deseaba capacitar a mi hijo para que alcanzara cuidadania entera necesitaba yo obtener conocimiento. Un conocimiento que progresivamente se convirtiera en poder.

Este conocimiento para mi, como para muchos otros padres en mi situacion, significaba aprender sobre la abogacia de padres intercesores. Significaba aprender tocante mis derechos y responsabilidades bajo la ley Educativa para Individuos con Deshabilidades conocida en ingles como Individuals with Disabilities Education Act (IDEA), Ley Publica 94-142. Esta ley que se decretó por el Congreso le permitió a mi hijo que recibiera una educacion publica apropiada y gratuita como tambien garantizar mis derechos como madre/padre de familia para involucrarme en el proceso educativo de mi hijo. Comprendi que si iva en realidad a ejercer mis derechos como companera por igual en este proceso era necesario aprender como implementarlos. Desafortunadamente, apesar de mis "derechos garantivados," no me di cuenta que iva e emprender todavia una lucha mayor en mi vida, la lucha para asegurar una educacion equitativa e igual en derechos para mi hijo.

La ley IDEA me habrá proporcionado con derechos como madre y participante pero desgraciadamente aquellos con los que debia de compartir como miembra integrante rehusaron aceptarlo. Apesar de estos obstrculos, continue aprendiendo y obteniendo experiencia para poder interceder por mi hijo, de esta manera me enteré de la desesperante necesidad de ayudar a otras familias. Comprendi que muchas otras familias, especialmente aquellas que no dominaban el ingles enfrentaban barreras más dificiles todavia. Aun sin embargo, su perseverancia para vencer esta barrera y otras para poder ayudar a sus hijos erá para mi digno de admiracion. Era un acto de *heroismo*.

En verdad, Angela L. Carrasquillo (1991) correctamente concluye lo siguiente de padres Latinos tocante la educación de sus hijos: "Hay indicaciónes que padres Hispanos desean mejor participacion en la educación de sus hijos." La señorita Carrasquillo añade que hay necesidad de involucrar a padres Hispanos en la educacion de sus hijos para asegurar que . . . todos los estudiantes aprendan. La señorita Carrasquillo eloquentemente emprende la introduccion de su libro:

El curso de la historia de Estados Unidos ha sido en mayor parte motivada por la busqueda de un sistema social que le permitiria a todo individuo avanzar segun sus habilidades y esfuerzos – sin ninguna barrera basada en raza, religion, sexo, o nivel socioeconomico. Sin embargo, esta no es la realidad de muchos ninos y adolescentes hispanos en Estados Unidos.

Por consecuencia, lo mismo corresponde a sus padres. Cuando a padres Latinos no se les da la bienvenida a apoyo en un sistema ajeno a sus necesidades, en verdad, sus hijos tambien sufren.

Afortunadamente, al nivel federal no se le ha ignorado a la causa de padres intercesores con sus esfuerzos de abogacia. Además, se está realizando la lucha de padres Latinos de niños con impedimentos en lograr que se nos reconozca y se nos apoye. Como madres y padres de familia debemos de aprovechar estas aportunidades y ampliarias apoyandonos y educandonos entre ambos. Por demasiado tiempo ya, la exclusión de nuestra gente de la sociedad dominante ha prevenido nuestro progreso. Se nos ha negado la participación esencial de una sociedad que se considera democrática. Pero nuestra perseverancia en tomar parte en la educación de nuestros hijos, apesar de las barreras que hemos encarado, promete un camino para poder cambiar esta desigualdad. Promete una direccion que nos puede dar el poder de capacitar a nuestros hijos para que lleguen a ser miembros productivos y contribuyentes de sus comunidades. Es un camino que me dice el querer es poder. Queramos y sigamos adelante. Unidos lo podemos lograr!

Bibliografia:

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"I propose a revolution of empowerment. A revolution that will empower every 21^{st} century American to live his or her God-given potential for self-determination, productivity, and quality of life."

JUSTIN DART,
1996 TASH
KEYNOTE
LUNCHEON
SPEAKER

You of TASH have provided cutting edge leadership, initiatives that have given millions of Americans with disabilities the potential to move from institutions, out of poverty and off of welfare to productivity and community. From independent living, IDEA, and de-institutionalization, to supported employment, supported living, assisted technology, self-advocacy, and the historic ADA, you have led the way. Your passionate principle and creativity have enlarged the lives of millions of people like me.

I congratulate you especially on the courageous leadership that many of you provided during Election '96. Thanks to you, people with disabilities won significant victories. We were more visible than ever before as serious participants in the political process. For the first time in history, both candidates for President publicly presented themselves as supporters of disability rights. Disability rights became a significant issue in a multitude of congressional, state and local races. Your efforts contributed to the election of many candidates who will support people with disabilities. But we still have a long way to go to reach the promised land, an America that empowers all. Relative to presidents past, Bill Clinton has a good disability batting average. We can help him make it better.

There is still a majority in Congress that is largely uneducated on our issues and, in many cases, outright hostile. The same is true on the state and local levels. The media still communicates devastating stereotypes. The future of Americans with disabilities is still in doubt. Now is the time for the disability community to close ranks, to assess the post-election situation and to create our agenda for the late '90s and the first years of the 21^{st} century. We must construct a firm political and policy foundation. Not simply to defend what we have, but to move forward.

What precisely is our problem? What is America's problem? What is America's potential? Angry about a run-away national debt and other growing pains of democracy, well meaning Americans are tempted by a politics of scapegoatism, escapism, and retreat. The politicians of retreat say socially responsible national government hasn't worked. They say go back to the "good ol' days." They say pass social responsibility from the Federal Government to the states, the cities, the businesses, the charities and the families. They say equality for people with disabilities is too expensive. They say that we are a small minority of tragic victims that can be taken care of through minimal welfare and charity. They say that many of us are better off in institutions, nursing homes and sheltered workshops. They say that many of us should not be allowed to vote. And there are those who say that the lives of people with severe disabilities are not worth living. They say that keeping us alive costs too much, that health care should be rationed, and that some of us should be assisted to die.

We the people with disabilities say NO! We say science and democracy offer a golden age of human culture, the good life for all in the 21^{st} century if we as a people have the will and the courage to act. Frustrated by a dream so close and yet so far, Americans hunger for a positive agenda, a vision based on shared values, common sense and a record of practical solutions. You of TASH have created the foundations of that agenda. Let us refine it and communicate it to America.

I propose a revolution of empowerment. A revolution that will empower every 21^{st} century American to live his or her God-given potential for self-determination, productivity and quality of life. I propose a new vision of free enterprise, free enterprise that systematically includes all in its processes, in its fruits. Let us unite. Let us shout together in one thundering voice. President Clinton, members of Congress, members of the media, Americans, we the people with disabilities, we the family and friends of people with disabilities have a message.

The politics of retreat is wrong. It will condemn millions of Americans with and without disabilities to isolation, poverty, welfare, charity and rationed health care. For some, there will be early death. Welfare and debt will increase. The economy, the quality of life of the entire nation will suffer. The politics of retreat is wrong. It violates family values, religious values, and business values. It violates Republican values and Democrat values. It violates American values. We the people with disabilities have a vision that is worthy of America.

People with disabilities are not a tragic minority. We are a magnificent majority. The majority of Americans will triumph over death to live with a disability at some point in their lives. Every family will have members with disabilities. Public policy that does not meet the needs of people with disabilities does not meet the needs of anyone. Science gives people with severe disabilities the potential to be 100 times more productive than our smartest, strongest ancestors of only 200 years ago. Decades of concrete

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"Public policy that does not meet the needs of people with disabilities does not meet the needs of anyone."

results prove beyond any doubt that we have the potential to be fully effective contributors to the economy and to the culture. Yet, for most of us that magnificent potential is severely limited by obsolete attitudes, obsolete systems, and obsolete policies. The life of every family and every individual is diminished. Our vision and America's task now is not to go back, not to defend the status quo. America's task now is to go forward. To keep the promise of Justice For All.

- Envision an America for all. Protect and implement the ADA and all civil rights laws. Increase investments in enforcement and especially in education to inform citizens, businesses and local governments of their rights and their obligations. Increase investments in legal services that give ordinary people real access to justice.

- Envision education for all. Reauthorize the IDEA, which strengthens federal guarantees that all children with disabilities will receive free and appropriate education in the least restrictive environment and maintains existing due process regulations in place. I commend you to support the TASH initiative to send thousands and thousands of postcards on the IDEA to the Congress. IDEA is just the beginning. We must work to guarantee lifetime education options, including higher education that enable all Americans with and without disabilities to meet the challenges of an age of exploding change and exploding complexity.

- Envision health care for all, defend and strengthen Federal guarantees of Medicaid and Medicare and other positive programs at the national, state and local levels. That, too, is only the beginning. Establish Federal guarantees of comprehensive, quality health care for all Americans. Guarantee consumer choice of doctors and treatments. Do not force treatment.

- Envision life for all. Rationing health care and vital personal assistance services and assisted death are not options of a civilized society. Our rights to live and to live free must be guaranteed by law. There should be a national conference on death, a forum in which we voice our right to live.

- Envision freedom for all. Establish Federal guarantees of consumer controlled long-term home and community-based services that empower all Americans to live and participate in their communities in manners of their own choosing. Let no American ever again suffer enforced isolation in an institution, a nursing home, a back room or any other place. Support Mike Auberger's CASA (Community Attendant Services Act) law.

- Envision jobs for all. Reauthorize the Rehabilitation Act in a form that streamlines processes that maintain the integrity of independence oriented services and make these services available to all who need them. This will mandate full consumer choice and full consumer control. Eliminate disincentives to work in the Social Security and health care systems. Create a continuum of integrated empowerment services, including supported employment that results in real jobs with real salaries for all who have the ability to work.

- Envision dignity for all. Establish welfare laws that encourage and empower all Americans to work and at the same time guarantee lives of dignity to all who truly have no other resource, including poor children with and without disabilities. Cuts in SSI payments to children with disabilities must be restored.

- Envision communities for all, which include access to housing, transportation, technology, and communications. All essential public and private facilities and services required by law must be accessible and affordable to all people. There must be no segregation of any kind.

- Envision government for all. Cut the fat, paternalism and the special interest out of government absolutely. Never weaken the authority of the United States to protect and empowers all its citizens. Create government that empowers the people, all the people, not just the governors and the health care companies that produce the culture and make the decisions that determine our lives.

- Envision responsibility for all.

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"Decades of concrete results prove beyond any doubt that we have the potential to be fully effective contributors to the economy and to the culture."

continued from page 17

> Balance the budget. We can do it without hurting anyone if everyone pays their fair share. No tax cuts for the wealthy until everyone receives quality health care and basic empowerment services. President Clinton, members of Congress, members of the media, Americans, we the people with disabilities, we the friends, we the families of people with disabilities will cooperate 100% to strengthen a free enterprise democracy.

We will cooperate with individuals, businesses and government at all levels to create common sense solutions that are good for all, but we are not going to be second class citizens anymore. We will work. We will live free and equal in our communities. We will fight to the end of time for equal access to the American dream.

My colleagues, this is an ambitious agenda with magnificent potential. It is within our power to create a quality of life for all Americans that exceeds the imagination of Utopian fiction. But can we afford to create the empowerment culture? Can we afford to expand public services, to build new communities in a time of deficit? We can't afford not to do it. The status quo is causing the deficit. Investment in empowerment will dramatically lower the overhead and increase the productivity and the quality of American life. It will create millions of new jobs. There will be an explosion of small and medium-sized businesses when guaranteed empowerment services liberate people to work where they choose. There will be an economic boom that will dwarf the industrial revolution.

America will renew its economic and moral leadership of the world. Nothing could be more Republican, nothing could be more Democrat, nothing could be more in harmony with family values, with reforming welfare, with reducing the deficit and nothing could be more in harmony with American heritage than empowering all Americans to participate in a free enterprise democracy.

My colleagues, empowerment in America is possible. We have the money, we have the talent, we have the technology. Now do we, as a nation, have the will and the courage to change? How can we possibly overcome the powerful lobbies for the status quo and for retreat? Who will save the dream? Look around this room. The buck stops here. We have accepted, we have chosen responsibility. We are responsible to every person with a disability. Every family with a disability in the world is responsible because

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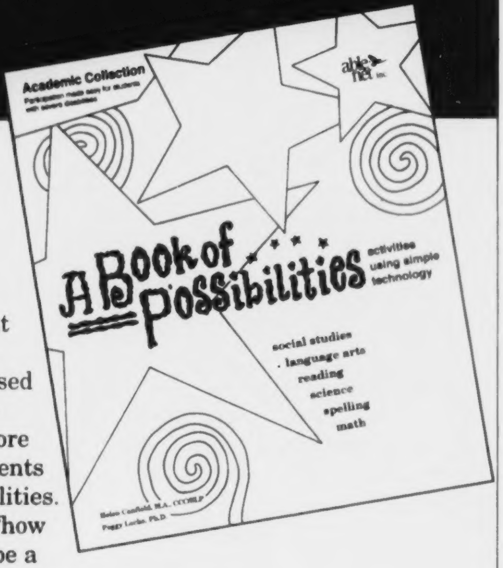
Inclusion really happens with you and the *Book of Possibilities.*



Simple-to-use technology is the key element in the more than 80 curriculum-based ideas designed to make learning more inclusive for students with differing abilities.

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America is the role model for the world. The world will follow what we do. We cannot afford to fail. You, who have done so much. We, together have got to do more. We have got to win. Now, where do we start?

We start by getting off of the defense and on to the offense. If enough of us, a critical mass, are willing to pledge our lives, our fortune and our sacred honor, if we are willing to make real sacrifices, if we are willing to go to our personal Valley Forges and to stay there however long it takes, we can prevail. Support TASH, absolutely. Don't wait for anyone. You don't need a title or invitation to make history. You can be a revolution of one. Speak out, reach out, mobilize. If you can motivate, if you can activate, if you can educate just a handful of those beautiful Americans who now are spectators in the struggle, we can win. Start with your families. Some families do gardens, some do sports, my family does revolution. Our offices are in the living room and bedrooms of our rented two bedroom apartment. All of my personal advocacy for the last fifteen years has been done through a computer, a printer and two telephones sitting on a $3.00 unfinished door in my bedroom.

Sometime ago I received a card from one of my foster daughters who was a volunteer for Justice for All. It reads "Love, empowerment, uprising. Happy Father's Day." It shows a painting of the storming of the Bastille. Lou Brown and many of you storm the 20th century Bastilles everyday. Mike Auberger, here today, and hundreds of our ADAPT colleagues have gone to jail many times for our rights. Extreme, certainly, but we are in a war. People are dying. My mother and brother took their own lives because they could not face the daily rejection of their humanity. There are still countries where babies with disabilities are killed.

Reach out with love and with truth to your kids, your husband, your wife, your brother, your sister, your parents. Reach out to friends, neighbors, colleagues in the office, in church. Reach out to businesses, to all in your community, and in the disability community. Reach out to the media. We've got to use the media better. Frank Laski put it well "we'ye got to blow away the smoke and fog that provides cover for current public policy that attacks people."

Friends, let's use politics. Get into politics as if your lives depended on it, because they do. And the lives of your children and grandchildren depends on it. Get into local politics, state politics, national politics, the elections of 1998 and 2000. Start today. Register voters, volunteer to work for good candidates. Educate opponents. Demand commitments. Flood the offices of candidates and the media with strong messages and strong people every day. Go to all the political meetings you can find. Put your signs, your bodies and your voices in their faces and in front of their TV cameras. Contribute. Yes, I'm talking about money. Even a small contribution of money puts you on a different list. Yoshiko and I give every dollar we can afford, and a few dollars we can't afford, to candidates who support people with disabilities.

Above all, colleagues, we of the disability community must stay united in the fundamental principles of disability rights: ADA, IDEA, empowerment. Unity is power. United we win, divided we lose. Let us overwhelm fear and fallacy with our vision of an America that empowers all. Solidarity forever.

National Search Alternative Day Activities

As part of its national search for promising practices in community integration for people with developmental disabilities, the Center on Human Policy is seeking examples of supports for people to engage in alternative integrated day activities other than supported work or traditional competitive employment. These could include:

- **someone who runs his or her own business**
- **someone who is engaged in volunteer work, leisure activities, or civic and/or community activities or organizations**

We seek examples based on the following principles:

- **the person is included in the community on an individualized basis**
- **supports (either formal or informal, paid or unpaid) are provided based upon individual need and desire**
- **activities and involvements are based upon the individual's interests and choices**
- **support is provided not only for engagement in activities but for social relationships as well. For inquiries or to make a nomination, please contact:**

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Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
315-443-3851
E-Mail: pmwalker@mailbox.syr.edu

DON'T LET THE FDR MEMORIAL COMMISSION HIDE HIS SOURCE OF STRENGTH —His Disability.

"FDR developed his strength of character, determination and discipline most distinctly as a result of having polio. We want him remembered as he was, in all his strength, courage and humanity. He would be comfortable, perhaps eager, in light of current increased understanding of disability issues, to share awareness of his disability with others. We urge an adequate inclusion of all facets of the man as he was, not as some think he ought to have been."

Letter to the National Organization on Disability from Anne Roosevelt on behalf of eight Roosevelt grandchildren, 4/29/96

Your help is URGENTLY needed! Since early 1995, the National Organization on Disability (N.O.D.) has been calling for the accurate depiction of FDR's disability in the memorial under construction on the Mall in Washington, D.C. There are three statues of FDR planned for the memorial - not one shows FDR in a wheelchair. **His disability is hidden.**

During his last 24 years, including 12 as president, FDR never took a step unassisted. He used his wheelchair every day. Hiding FDR's disability in the memorial is an affront to America's 49 million citizens with disabilities and a half-billion people worldwide.

Future generations of visitors from throughout the world will learn that FDR led the United States out of the Great Depression, and commanded to victory the mightiest fighting force ever assembled. Yet, they will not know that he did it all from his wheelchair.

Time is running out! Join the N.O.D., the FDR in a Wheelchair Campaign, and others who support the depiction of FDR in a wheelchair:

"It is my opinion that FDR should be shown for what he was - a courageous man who had infantile paralysis and still led our nation."

Former President George Bush, 4/29/96

"It is important to Americans with disabilities, and important as a symbol of how American society perceives its disabled people, that the memorial depict the man as he was: tall, strong, heroic and disabled... Don't let them steal our hero!"

Hugh Gallagher, author, *FDR's Splendid Deception*

"Omission of FDR's handicap is a crime against his spirit."

Hugh Sidey, Time Magazine, 5/20/96

73% of Americans favor showing FDR's disability clearly as part of the memorial.

1995 N.O.D./Harris Poll

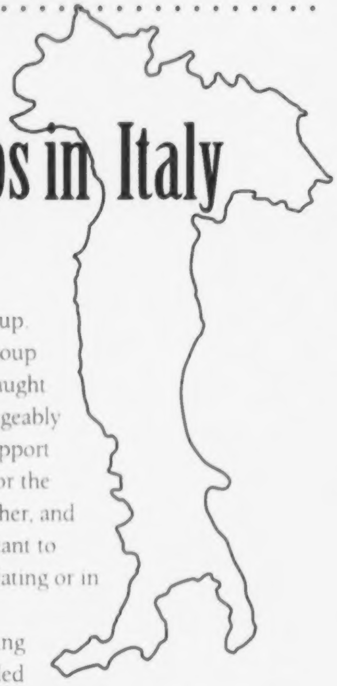
ACT NOW! Let the President and the FDR Memorial Commission Co-Chairmen know that the FDR Memorial **must show President Roosevelt's disability.**

Write: President William Clinton
Honorary Chairman, FDR Memorial Commission
The White House
1600 Pennsylvania Avenue, N.W.
Washington, D.C. 20502
Tel.: (202) 456-1111
Fax: (202) 456-2461
E-mail: president@whitehouse.gov

Write: Senator Mark Hatfield
Senator Daniel K. Inouye
Co-Chairmen, FDR Memorial Commission
825-A Hart Senate Office Building
Washington, D.C. 20510
Tel.: (202) 228-2491
Fax: (202) 228-1010

EVERYONE BELONGS:

School Inclusion and Social Relationships in Italy



CAROL BERRIGAN AND DENNIS TAYLOR

Background: Inclusion in Italy

"Italy has become a laboratory for the rest of the world. Other nations send representatives to observe our schools. Many countries started by integrating students with disabilities gradually and years later they still have special classes and special schools." Dr. Raffaele Tortora spoke these words to participants of a Syracuse University seminar observing inclusive education in Italy. Dr. Tortora is the National Director of Study and Development of Innovations in Education in Italy. He went on to say, "Inclusion is not a consideration with us; inclusion intimates that there also can be exclusion. Students with disabilities are simply students. It is a matter of decency. It is a way of life."

What influenced people to begin total inclusion without the intermediate stages endemic to other nations? Prior to the establishment of Italy's National Law 118 in 1971, which mandated the right of compulsory education for children with disabilities in regular classes of public schools, inclusion of all children was already beginning in some areas of Italy.

Leaders of the movement that welcomed all students to regular public education in Italy cite four elements that emerged as critical to the movement's success: (1) support teams (operatori sociali) for the classroom teachers comprised of special education teachers (sostegni), physicians, psychologists, social workers, nurses, speech and physical therapists; (2) sharing of responsibility by parents, teachers, medical personnel, and community, forging an effective coalition to create an alternative to the traditional medical model for children with disabilities; (3) educating the public, using various media and public meetings; and (4) the presence of charismatic leaders early on, such as Dr. Franco Basaglia and Dr. Adriano Milani Comparetti. Their passionate concern was the right of every human being to full participation in society. They saw limitless benefits for all children, nondisabled and disabled, to learn together. They saw the segregated individual's potential destroyed. They acted on these convictions by closing institutions and joining parents to present their children in the neighborhood school. In 1984, Dr. Adriano Milani Comparetti stated, "When we began in the late sixties we found that the best approach to acceptance was to have students appear at their neighborhood schools. We found that attitude changes were made in response to concrete happenings, not to abstract concepts."

Two decades ago, the Organization for Economic Co-Operation and Development (OECD), headquartered in Paris, cited Italy as the most advanced country among its member nations in its policy to include all children with disabilities in regular public schools. An OECD publication (1994) stated:

"Integration in Italy consists in placing virtually all children in ordinary classes, and results in the presence in mainstream schools of multi-handicapped or severely handicapped children who would be placed in special schools in any other country. These children are physically integrated in the ordinary classroom, and work with the class teachers and/or the support teacher. The support teacher works in the classroom, and rather than take the child individually, teaches the disabled child as part of a small group. Such a group may be taught interchangeably by the support teachers or the class teacher, and this is meant to avoid isolating or in any way stigmatizing the disabled child who is receiving special education provisions."

The Italy model is described in the OECD publication as having the primary focus of attention on a "search for better interpersonal interaction," one with the closest links to past and present experiences of the person, rather than having the primary focus on better equipment. Professor Andrea Canevaro, University of Bologna, writes that a child with a disability,

"is not respected if he is simply left to live with his handicap as best he can, but neither is he respected if the fact that he is handicapped is denied. If, on the other hand, his identity and his originality...which includes his handicap...are encouraged to assert themselves and to increase, he is being respected. This is active, realistic consideration, in regard to both his situation and his relationships." (Canevaro, 1984).

Inclusion and Friendship

The outcome of relationships developed or reinforced in schools of Italy is the flourishing of friendships and positive social relationships. Friendships for all students, with and without disabili-

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ties, are formed and nurtured in their natural setting. This ecological approach to personal development is contrasted with the contrived models that occur in segregated, exclusive, and mainstreamed arrangements.

Support for friendships in young people of all levels of ability, and the nurtured natural development of positive relationships, is a keystone of Italian educational philosophy. Cooperative and collaborative teaching models encourage possible social exchanges between individuals of diverse abilities on a regular basis. An important piece of this philosophy is the respect for the integrity of the neighborhood's school and the diversity contained within as a basis for community, friendships, and social relationships.

We have moved slowly in the United States. We have pockets of exemplary inclusive education, but nationwide the struggle has not abated. Celebrated litigation, case by case, establishes precedents. What a travesty that our national law has to be litigated in school district after school district because parents want an inclusive setting for their children! Over and over again they have had to battle for the rights of their children. It is commonplace in the United States for school districts to reject regular placement of students with significant disabilities. It is commonplace in Italy that students with significant disabilities go to regular classes of their neighborhood schools.

Current research in educational policy for individuals with disabilities is examining the social relationships individuals have, particularly the types, nature, and quality of friendships they experience. It is clear that substantive friendships lend meaning, self-esteem, structure, and support to the lives of everyone. Full inclusion is clearly fundamental to the achievement of positive relationships in Italy, and indeed, everywhere.

Related Readings on Italy

The following articles provide further information about policy and practice related to inclusion in Italy:

- Brown, B. (1990, Summer). Integrated schools in Italy make it possible for everyone. *entourage*, 5(2,3), pp. 15-17, 20.
- Canevaro, A. (1994). *Education at a glance.* OECD Publication. (USA Information Center, 2001 L Street, N.W., Suite 700, Washington, DC 20036-4910.
- Gerry, M. (1989). *Italy: The transition of young persons with disabilities.* Washington, DC: U.S. Department of Education.

  The integration of disabled children into mainstream education: Ambitions, theories, and practices. OECD Publication (see address above).
- Oakland, T., Cunningham, J., Meazzini, P., & Poulson, A. (1991). An examination of policies governing the normalization of handicapped pupils in Denmark, Italy, and the United Stated. *International Journal of Special Education*, 6(2), 386-402.

  Vitello, S. (1991). Integration of handicapped students in the United States and Italy: A Comparison. *International Journal of Special Education*, 6(2), 213-222.

Related Readings on Promoting Friendships in School

The following articles provide further information related to promoting friendships in school.

- Falvey, M.A., & Rosenberg, R.L. (1995). Developing and fostering friendships. In M.A. Falvey (Ed.), *Inclusive and heterogeneous schooling* (pp. 267-283). Baltimore: Paul H. Brookes Publishing Co.

  This chapter begins with a definition of friendship and a discussion of conditions essential for friendships to develop and benefits of friendship. It then presents strategies for fostering friendships in the areas of: curricular considerations, instructional approaches, establishing social opportunities, and creating community opportunities.

- Pearpoint, J., Forest, M., & O'Brien, J. (1996). MAPs, Circles of Friends, and PATH. In S. Stainback & W. Stainback (Eds.), *Inclusion: A guide for educators* (pp. 67-86). Baltimore: Paul H. Brookes Publishing Co.

  Frequent opportunities and close proximity are not always sufficient for children and adolescents to feel connected to each other and to build a network of friends. Thus, a number of tools have been designed to help facilitate such connections. This chapter describes three person-centered tools, Making Action Plans (MAPs) (formerly McGill Action Planning System), Circles of Friends, and Planning Alternative Tomorrows with Hope (PATH), and provides examples of the use of each.

- Stainback, W., & Stainback, S. (1990). Facilitating peers supports and friendships. In W. Stainback & S. Stainback (Eds.), *Support networks for inclusive schooling* (pp. 51-63). Baltimore: Paul H. Brookes Publishing Co.

  This chapter presents strategies that teachers and support personnel can use to promote informal peer support and friendships. Some of these strategies include: promoting proximity, encouraging support and friendship development, teaching peer support and friendship skills, fostering understanding and respect for individual differences, acting as a positive support and friendship model. In conclusion, the authors note that it is important to encourage and foster friendship and support behaviors in all students.

- Strully, J.L., & Strully, C. (1996). Friendships as an educational goal: What we have learned and where we are headed. In S. Stainback & W. Stainback (Eds.), *Inclusion: A guide for educators* (pp. 141-154). Baltimore: Paul H. Brookes Publishing Co.

  The chapter begins and ends with the authors' descriptions of some of their daughter's experiences with relationships and friendships. Based on this, they include discussion of issues to consider related to friendship; what needs to be in place for friendships to develop, and important themes in making friendships. The authors conclude that relationships are important to all of us, and that developing friendships in school for all children is one of the most important accomplishments that parents and educators can undertake.

- Carol Berrigan, Ph.D., is Adjunct Professor at Syracuse University and a staff member at the Center on Human Policy. Dennis L. Taylor is a Doctoral Candidate in Teaching and Leadership/Art Education at Syracuse University.

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Once again, the Federal Law that guarantees a free and appropriate education for ALL children is at risk of being dismantled. A number of groups have joined together to endorse the following position. Please add your voice to those of the following individuals and groups who have endorsed this position:

A Good I.D.E.A.

Keep the Rights, Realize the Promise. Part B Already . . .
Protects Kids, Protects Schools, Protects Families

DON'T CHANGE IT!! MAKE IT WORK!!

1) Don't change Part B of the Individuals with Disabilities Education Act (IDEA): It is permanently authorized.
2) Permanently authorize Part H: Early childhood education for children from birth through age 3.
3) Reauthorize the discretionary programs: They were intended to make Part B effective.
4) Help IDEA meet the promise: Increase appropriations for IDEA.

Affiliation: ______________________ List affiliation only? ______________________
Name: ______________________ List name first? ______________________
Address: ____
Phone: ______________________ Fax: ______________________
Email: ______________________ Congressional District: ______________________

PLEASE FAX BACK TO: TASH (410) 828-6706
QUESTIONS? CALL MARCIE ROTH @ (410) 828-8274 X104

You can also find this form on our home page at www.tash.org along with a template for postcards to send to the President, Department of Education and Congress to inform them of your position.

This position has been endorsed by the following groups as of January 16, 1997:

Center for Law and Education
National Down Syndrome Congress
Schools Are For Everyone (SAFE)
The Autism National Committee
PACER Center-MN
Family T.I.E.S. Network-IL
Federation for Children with Special Needs - MA
IL Planning Council on Developmental Disabilities
Public Interest Law Center of Philadelphia (PILCOP)
PEAK Parent Center-CO
Endependence Center-VA

OH Coalition for the Education of Children with Disabilities
MI Citizens Alliance to Uphold Special Education
MD ABC Coalition
Institute on Community Integration-U of MN
Autism Support & Advocacy in PA (ASAP)
Parent Information Center-NH
Exceptional Children's Assistance Center-NC
Parent Education Network-PA
Partners Resource Network-TX
And Over 50 Additional Parent Training and Information Centers

1997 TASH Conference

DECEMBER 10-13, 1997

"We the People, ALL the People"

The 1997 TASH Conference "We the People, ALL the People" will be held at the Boston Sheraton December 10-13, 1997. Pre-Conference TASH Tech workshops will be held on Wednesday, December 10, 1997. The TASH conference is known for extraordinary sessions that are a combination of personal experience, professional knowledge, and incredible enthusiasm and spirit. Come join the thousands of family members, self-advocates, professional, advocates, and community members who have been instrumental in shaping the inclusion revolution!

TASH encourages presentations that are partnerships between people with varying viewpoints and experiences. Panels that are composed of self-advocates, parents, family members, researchers, graduate students, and professionals are encouraged to submit. Panels are also encouraged to represent multicultural, under-served, and varying socio-economic viewpoints.

Presentations must reflect the values and resolutions of TASH. Please note the specific priority areas of interest designated on the 1997 Call for Presentations.

Sheraton Boston Hotel & Towers

1997 Call For Presentations

1997 TASH Conference
"We the people, All the people"
Sheraton Boston Hotel and Towers
December 10-13, 1997

TASH encourages presentations that are partnerships between people with varying viewpoints and experiences. Panels are strongly recommended that are composed of self-advocates, along with parents, family members, researchers, graduate students, and/or professionals. Panels are also encouraged to represent multicultural, under-served, and varying socioeconomic viewpoints. Presentations for the Community Living Strand will require such partnerships for acceptance.

Deadline for submission is March 31, 1997.

Send original proposal *with (3) three copies* to:

Denise Marshall, TASH
29 West Susquehanna Ave., Suite 210
Baltimore, Maryland 21204
e-mail: dmarsh@tash.org (in text or Word files)

To avoid duplication and illegible copies - Please do not FAX application or proposal. You may fax a letter indicating that the proposal has been mailed by the deadline. Proposals received after the deadline will be considered based on available space.

Proposal Instructions

1) An abstract must be sent along with the application on the reverse side. Abstracts should (1) describe the topic or issue addressed, (2) provide an overview of the content, (3) describe the importance and contributions of the session, (4) list presenters involved, and (5) describe the session format - i.e. skill-building, program discussion, panel, etc. Priority for sessions will be given to interactive, practical, skill-building sessions.

2) Proposal content must reflect the values and resolutions of TASH. TASH is dedicated to disseminating information that reflects both the ideals and the pragmatic realities of pursuing the goals of equity, social justice, diversity, and full community participation for people with disabilities. The proposal title, description, and all content of presentations must use "people first" language.

3) Please limit the abstract to 300-600 words (1 - 1 1/2 pages). Do not send any other materials. You may submit the information on the application form or in alternate format, as long as all of the information requested is included. The form is available on TASH's web page: http://www.tash.org.

4) Please complete all sections: coordinator information, grid, session description, **and contact information for co-presenters.** TASH encourages you to include a variety of co-presenters in your sessions. Please include presenters who are reasonably certain of attending. Use another page if necessary.

5) In requesting the session format, please keep in mind that 1 hour and 2 hour and 15 minute presentations are reserved for interactive workshops with an audience. Poster sessions are table top "exhibits" that allow personalized opportunity for discussion. Posters are highly interactive and valuable sessions.

6) We strongly encourage presenters to be TASH members. ***All*** presenters are required to pay conference registration fees and rental of audio/visual equipment for their session. National TASH members, self-advocates, parents, and family members are eligible to register at a reduced rate. Conference registration forms will be sent with letters of acceptance in June, 1997.

-See Other Side for Application-

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For more information please call Susan E.Gurry, Ed.D. at 617-349-8499 or 800-999-1959, ext. 8499 or e-mail sgurry@lesley.edu

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The TASH Multicultural Interest & Action Group

BY SUSIE SCHAEFER

The inception of the TASH Multicultural Interest and Action Group dates back to the early 1980s as the International Committee. At that time several members of the group, led by Carola Murray-Sergert, got together at the TASH national conference in San Francisco to discuss our interest in international issues. Some of the issues discussed included: the needs of people with severe disabilities in third world countries; the problems confronting families and individuals whose primary language was not English; and situations where children and/or other family members were misdiagnosed as having severe disabilities because of language issues.

We organized ourselves and divided into subcommittees that we labeled as Asian and/or Pacific, Spanish-speaking and European. In our early years as the International Committee, we welcomed TASH conference attendees from other countries. The committee also offered forums for professionals to share experiences while working in other countries and generally tried to increase diversity in the ranks of TASH. Gunnar Dybwad, Lou Brown, Wayne Sailor, Dorothy Lipsky, and others all gave us encouragement to develop our committee as an important part of TASH.

In the early 1990s, the group expanded in size and scope and began to recognize and concentrate on multicultural issues. Later, we actually divided into two committees. We began to organize conference strands and to emphasize the need for diversity within TASH. We challenged the membership to elect representatives of color to the National Board, rather than have them appointed ex-officios by the Board. Gwen Benson was elected and has expertly represented our committee and people of color. Carmen Ramirez later joined the Board and has become a key member. Recently, David Belton was elected to the TASH Board. In 1995 with the reorganization of the TASH committee structure, we became known as the TASH Multicultural Issues and Action Group.

Over the years some of the committee's goals have included better involving and supporting families of color and those for whom English is not the first language. The committee has also sought to increase the number of professionals of color in teaching and training people with severe disabilities. We have long recognized the need for leadership and commitment by TASH to develop greater diversity in our membership. Efforts to reach out to families whose first language is not English, as well as provide information in other languages, are needed. As indicated, the TASH Multicultural Group has always been, and remains, committed to welcoming and including a wide variety of individuals and families at all levels of TASH. Because group members are spread across the U.S. (and around the world), we have concentrated on our national conferences and tried to use our time together at national conferences in positive ways. In our early years it was a struggle to get presenters to discuss multicultural issues, but eventually our group was able to sponsor a conference strand.

Presentations by committee members and others at our national conference have helped to increase the awareness of TASH members of the diversity of our population. We have grown to recognize cultural issues and strengths in our local communities and schools. This past year, we made a conscious effort to encourage discussion of multicultural issues in all presentations rather than offer a separate conference strand. We have also attempted to have the conference include music and performances by ethnic groups. This will continue as we begin to prepare for a very diverse, multicultural conference next year in Boston.

Over the past several years, members of the Multicultural Interest and Action Group have participated in the discussions of the Community Living Group. The intent has been to raise the issues of all segments of our communities, including various ethnic and cultural groups. Next year the groups will join together in a partnership and will offer greater opportunities for discussion and sharing.

The TASH Multicultural Interest and Action Group, along with other TASH Action Groups, will continue efforts for recruitment and training of professionals of color. We will also continue to support the organization and leadership by groups, such as the Festiva Educativa, and the Grassroots Coalition. As we enter the start of a new year, look for our conferences, both local and national, to be representative, meaningful and supportive for all.

Susie Schaefer is the former Coordinator of the TASH Multicultural Interest and Action Group. Lynda Baumgardner is the Group's new Coordinator. For more information on the Group's activities, contact Lynda at: P.O. Box 593, Lingle, Wyoming 82223, (307) 837-2918.

able·net inc.

AbleNet's® Inclusion Award 1997

To recognize todays leaders in breaking down barriers to inclusion for persons with severe disabilities, AbleNet will present an annual, worldwide inclusion award. Each year, an innovative, visionary team of people who creatively demonstrate best practices will be honored for their exemplary efforts to foster participation. By calling attention to how these leaders worked together to change the everyday lives of persons with disabilities and by honoring their commitment and courage, AbleNet hopes to inspire a world without limits for persons with disabilities.

The 1997 AbleNet Inclusion Award recipient (one team) will receive a $500 gift certificate for AbleNet products and a $500 cash award to defray the costs of attending the 1997 Closing the Gap Conference to accept the award.

Awards & Recognition

AbleNet will honor one team of individuals as recipient of the AbleNet Inclusion Award. Any team of individuals as described in the official application process is qualified to apply. The winning team will be officially announced at the 1997 Closing the Gap Conference.

How to Apply

Send us a brief summary describing five of the most innovative strategies/activities your team has developed that fosters inclusion of an individual with severe and profound disabilities. Any activities designed to create opportunities for inclusion into academic, recreational, vocational or community settings should be shared. The activities need not include the use of AbleNet products.

To enter, just fill out the official application form describing your ideas and forward it along with a minimum of two letters of support from individuals who are familiar with your teams activities. Entries must be received by midnight March 31, 1997.

For more information or to receive an application, contact AbleNet, Inc., Attention: Inclusion Award, 1081 Tenth Avenue SE, Minneapolis, MN 55414 or phone us at (800)379-0956 U.S. & Canada or (612)379-0956, Fax (612)379-9143.

An Open Invitation to

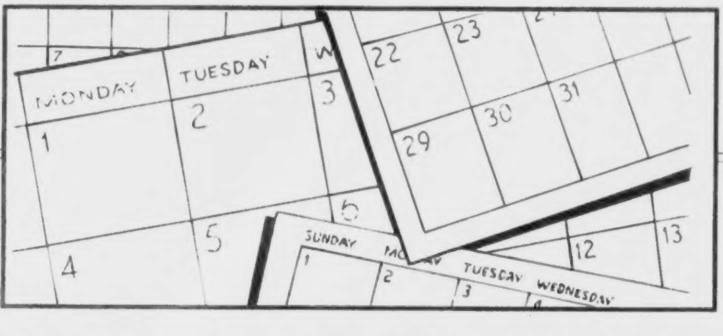
Grandparents and Parents of Children with Special Needs

Donald Meyer and Patricia Vadasy are creating a book for grandparents of children with special needs for Woodbine House. To make this book as practical and "real" as possible, Don and Pat are seeking contributions from grandparents who are willing to share their thoughts about what it means to have a grandchild with special needs. And, because "grandparent issues" are "generational issues", Don and Pat are also seeking contributions from parents and others who know how a child's disability can affect all family members.

To obtain a copy of a Contributor's Packet, please contact Don Meyer by mail, e-mail, fax, or phone. When requesting a packet, please identify yourself as a parent, grandparent, or other family member. The entire Contributor's Packet may also be found at Sibling Support Project's Web Page at the following address: http://www.chmc.org/departmt/sibsupp

DON MEYER
Grandparent Book Project c/o Sibling Support Project
Children's Hospital and Medical Center
P.O. Box 5371, CL-09 • Seattle, Washington 98105-0371
Telephone: (206) 368-4912 • Fax: (206) 368-4816 • E-mail: dmeyer@chmc.org

Don and Pat are authors and editors of several books, including Uncommon Fathers, Sibshops, Grandparent Workshops, The Father's Program, and the children's book, Living with a Brother or Sister with Special Needs.



CALENDAR PHOTO CONTEST

Do you have one of those one in a million pictures that really does say more than words? If so, we'd like you to send it in and have a chance to be part of the "We the People, ALL the People" calendar. Twelve pictures that capture the spirit of true community inclusion for all will be chosen to be used in a 1998 TASH calendar. Please send your entry in by June 1, 1997. Photographs will not be returned. Contestant is responsible to obtain permission from the people in the photographs prior to submission.

CALENDARS WILL BE AVAILABLE AT THE 1997 TASH CONFERENCE

Send Pictures to:
DENISE MARSHALL — PHOTO CONTEST
TASH • 29 W. Susquehanna Ave., Suite 210 • Baltimore, MD 21204

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For more information please call Susan E. Gurry, Ed.D. at 617-349-8499 or 800-999-1959, ext. 8499 or e-mail sgurry@lesley.edu

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☐ I am interested in attending an Information Meeting.

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Special Education – Severe Disabilities –

The Department of Special Education, Peabody College of Vanderbilt University, invites applications for a senior faculty member in the area of severe disabilities, broadly defined to include severe mental retardation, multiple disabilities, sensory impairments, and/or severe behavior disorders. Applicants should have interests in school aged learners. Applicants who have a strong history of external funding for their research and training efforts, and who also have a commitment to undergraduate and graduate instruction are especially encouraged to apply. The successful candidate will be expected to be an active contributor to the overall success of the Department and to work collaboratively with investigators from other disciplines associated with the John F. Kennedy Center for Research on Human Development, one of 14 centers for research on mental retardation and developmental disabilities supported by the National Institutes of Health.

Vanderbilt University is an equal opportunity, affirmative action employer with a strong institutional commitment to diversity in all areas. The university actively seeks applications from women, minorities, and individuals with disabilities.

Applicants should send a letter of interest, vita, three publications, and the names and addresses of three references to Steven F. Warren, Chair, Severe Disabilities Search Committee, Peabody College, Box 328, Vanderbilt University, Nashville, TN 37203. Preliminary inquiries may be directed to Steve Warren at (615) 322-8277 or Warrensf@ctrvax.Vanderbilt.edu

CONFERENCE ANNOUNCEMENT

"Children who are Medically Complex or
Technology Dependent:
Meeting the Needs of Children and Families"

March 5-7, 1997
Sheraton Society Hill Hotel
Philadelphia, PA

Presented by
Ken-Crest Services in collaboration with the
Philadelphia Department of Human Services.
Sample topics: managed care, unique program models, funding, ethical, medical and child welfare issues.

Please call (215) 844-4620, x122
or visit our new web site to request a conference brochure:
http://www.kencrest.org/~kencrest/medfrag

Director of Training

Res-Care, Inc., the nation's leading proprietary provider of supports and services to persons with developmental disabilities, is seeking a director of training for its Division for Persons with Disabilities. Preferred candidates will have 3-5 years of experience in the MR/DD field with at least one year in full-time training capacity. A bachelor's degree in human services or related field is required. He/she should also possess excellent computer skills including knowledge of WordPerfect 6.1, Visio, Harvard Graphics and D-base. Responsibilities will include developing and coordinating training supports for DPD operations, training curricula development, maintenance of in-house professional certification programs, coordination of annual training conferences and overall programmatic support as required.

For more information please mail your resume in confidence to Anita R. Bowles, Director of Management Recruitment, Res-Care, Inc., 10140 Linn Station Road, Louisville, KY 40223 or fax to (502) 394-2206. EOE

Res-Care
INCORPORATED

CORRECTION:
Page 24 of the December 1996 *Newsletter* listed an incorrect telephone number for Norman Kunc and Emma Van Der Klift at Axis Consultation & Training Ltd.
To order a copy of the video, "Credo for Support", contact Axis at (604) 754-9939.
We regret any inconvenience caused by this error.

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on language "that emphasizes the humanity of people with handicaps." Terms such as "the autistic," "the retarded," and "the severely handicapped" refer to characteristics, not individuals. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Executive Board

Frank Laski, *President*
Mark Partin, *Vice President*
Liz Healey, Chair of the Executive Committee
Dianne Ferguson, *Secretary*
Mike Auberger, *Treasurer*
Nancy Weiss, *Executive Director*
David Belton
Doug Biklen
Kathy Boundy
Barbara Buswell
Lori Goetz
Robert Holland
Michael Kennedy
Liz Obermayer
Ian Pumpian
Carmen Ramirez
Linda Rammler

MEMBERSHIP INFORMATION

Name: ____________________

Address: ____________________

City/State/Zip: ____________________

Telephone: (   ) __________ Fax: (   ) __________

Please Check Appropriate Categories
(not more than three):

( ) Administrator
( ) Adult Service Provider
( ) Case Manager
( ) Day Personnel
( ) Early Childhood Services
( ) Educational Adult Services
( ) Educator (University/College)
( ) Early Intervention Specialist
( ) Friend
( ) Gov. Personnel (Federal, State, Local)
( ) Higher Education
( ) Human Services Provider
( ) Interested Individual/Advocate
( ) Legal Administrator
( ) Occupational/Physical Therapist
( ) Paraprofessional/Direct Care
( ) Parent/Family Member
( ) Primary Care Provider
( ) Personal Assistant
( ) Professional Advocate
( ) Psychologist
( ) Regular Education
( ) Residential Services
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Student (College/University)
( ) Support or Related Services
( ) Supported Employment Personnel
( ) Teacher (Direct Service)
( ) Teacher Trainer
( ) Vocational Services
( ) Other

General Membership (individual) .... $85.
Agency/business/university/college/library/school .... $190.
(allows three conference attendees)
Self Advocate, Parent, Full Time Student, Direct Careworker/Paraprofessional/Personal Attendant (for whom payment of full fee would present a hardship) .... $45.
Family (group rate) .... $130.
Lifetime Member: .... $1000.

All dues are $15 higher for members outside the U.S. & Canada.

If you would like to charge your membership, please fill in the necessary information:

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Cardmember __________

Expiration Date __________

Signature __________

( ) I would like to arrange to spread my payments out. Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

How did you learn of TASH: __________

What, in particular, inspired you to join: __________

What other disability organizations do you belong to: __________

Referred by: __________

If you are applying for a student membership, please provide the following information:

Department __________

College/University __________

Student I.D. Number __________

Anticipated year of completion __________

( ) Please check here if you would like us to send information about your local TASH Chapter.

MOVING?

Please notify* TASH *of your new address.

Please make check payable to: **TASH**
Address: **29 W. Susquehanna Avenue**
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Telephone: **410/828-8274 Fax: 410/828-6706**

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Address Correction Requested

IMPORTANT!
1997 Call For Presentations
Inside!

JANUARY 1997

TASH Newsletter

VOLUME 23 ISSUE NUMBER 2 FEBRUARY 1997

A GOOD I.D.E.A.

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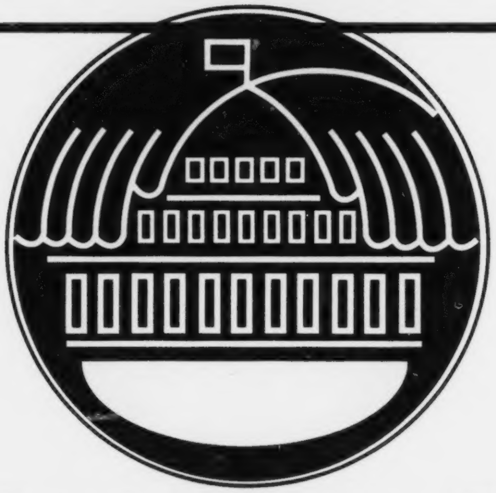

Realize the Promise

Don't Change It Make It Work!

INSIDE: Congressional Testimony on IDEA, Parental Perspectives and Community-Based Instruction

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A LETTER TO MY DAUGHTER'S TEACHER, FROM MY HEART

BY KAY DRAIS

Dear Teacher,

I know you hold a very deep and rich part of your heart open to all of the exceptional children that you laugh, cry, struggle and celebrate life with every day. Please do not construe this letter as personal criticism. I admire your commitment, tenacity and your love for the children you serve. I have no doubt that you are a blessing in their lives. I write first, to be true to myself and my personal inspiration, and also because when you find something good in life, the only contribution available is to offer what one can, in the hopes that the good can grow ever more good.

When we talked on the phone, and you referred to "the level of cognitive impairment" of Jessica, I felt as though I had quite unexpectedly been washed away in a tidal wave of oblivion. I do not see Jessica as impaired. I see her as different than most of us in general terms, but different is not impaired. Synonyms for impaired are defective, damaged, ruined, incapacitated, mutilated--synonyms for different are distinct, non-uniform, differing, dissimilar, unusual, uncommon. I prefer to believe, and my heart very clearly tells me, that my daughter is uncommon, not defective. I guess I had been working under the misconception that you, like me, did not put much stock in such labeling, and in fact, avoided such frighteningly limiting notions as lenses through which to view children.

Once I finally groped my way though my incredulous shock, my first impulse was to snatch up Jessica and RUN -- run as far and as fast as possible away from Jessica's school, far and fast away from what I consider to be a spiritually primitive educational system, and far and fast away from the fears, judgements and cynicism of people who simply do not understand my daughter. If being in school for Jessica requires being destined to face preconceived notions of profound limitations on a daily basis, then quite simply, who needs it? I honestly believe she would be better off without it. Perhaps that is why she is so emphatically resistant to our efforts to "educate" her.

I quickly realized however, that running away is not the answer. For I would have to spend the rest of my life running from lack of understanding and it is hard to change misunderstanding when one is clipping along at a breathless sprint. Instead, I ask you to please consider how deeply the images and concepts you hold of your children do, in fact, enter significantly into the equation of your relationship with them, and the natural outcome of that relationship.

Jessica is not a mistake, she is a gift. Her greatest gift is that her apparent disabilities tend to highlight how we as individuals, communities and institutions tend to respond to that which we do not understand. Certainly it is comforting and convenient to label the unknown as inferior/impaired in one fashion or another, because then it can be neatly set aside and life as we know it can be gotten on with.

People with apparent disabilities stop us dead in our tracks. I know, because I was stopped dead in my tracks when I learned that Jessica was not-your-average newborn. However, I have come to understand that the way we respond to people who are different in any way, clearly reflects our own willingness to either expand our horizons, or to shrink back in fear. It is very clear to me now, that the manner in which we interface with people with apparent disabilities is far more reflective of our own personal capacities than of those of the person with whom we interface.

In basic terms, IQ testing measures "recognizable" capacity to "adapt" to preconceived patterns as quickly as possible. What about imagination? What about spontaneity and creativity? What about personal integrity? To conform or adapt to society as it functions today in general terms, would be to strive to learn to manipulate, to live in fear, and to live with frustration, insensitivity, and greed. I have no desire to adapt to that, and I am glad my daughter appears to have little interest as well.

SO WHAT DO I WANT? I want us to hold our judgement, interpretations and projections of each other lightly. I want all of us to be brave enough to trust that the beauty and goodness of each of us is innate and sufficient, just as we are. I want myself and others to be patient with and accepting of Jessica's relationship with this realm, to look for what we share and "celebrate", and to gift one another with our uniquenesses. I want myself and others to grow beyond a need to insist that our own particular version of life on earth is the only valid one. As far as I am concerned, unless someone can feel and convey genuine acceptance of Jessica exactly as she is right now, there will be no platform with any integrity, upon which to build meaningful experiences of growth and unfoldment within Jessica personally, or in relationship to her.

Indulge me for a moment, and imagine yourself to be a violet growing smack dab in the middle of a bed of daisies -- and all of your (short) life, the multitude of daisies surrounding you seem frustrated that you are different. They try to the best of their abilities to turn you into a daisy, despite the fact that you, while very similar in many ways, are also very different than the other flowers who share your life. Would it serve you to try to be a daisy when it is clearly true that you aren't one and never will be? How would it feel when the well intentioned daisies around you continually insist that you look and act more like a daisy than the violet that you truly are? Have you ever picked a violet and suddenly found yourself wishing that it were a daisy instead? Wouldn't you be glad of its violetness and wouldn't that be sufficient, even rather exquisite, in and of itself? Is it any different with people?

I imagine, dear teacher, your mind is now thinking, "well, this world is predominantly of, for and by the daisies". And true, you have generously and with much self-sacrifice spent a good deal of your time patiently teaching the violet a few daisy tricks, so that she can function effectively in the daisy bed. After all, she is growing there. My point is, that if she has to deny her essence as a violet, there is no value at all in learning daisy skills. If daisy skills, however are optional, and she can be accepted as the violet that she is, she will gracefully and sweetly unfold into the fullness of her beauty, warmed by the sun, and nurtured by the trust and openheartedness of her surrounding daisies.

Violets, beloved friend and teacher, are NOT impaired daisies. I thank you dear teacher, from the very essence of my self, for your wondrous dedication to this fabulous bouquet of children you have welcomed into your heart. ❤

FROM THE EXECUTIVE DIRECTOR

BY NANCY WEISS

Many TASH members have expressed concern about TASH's name. A number of people have told us that their reasons for not joining or re-joining TASH have to do with their discomfort around the name. In addition to containing language that is somewhat archaic, the name may imply misinformation about who falls, or does not fall, within the circle of our advocacy and activities.

Here at central office, we frequently get phone calls asking for clarificat ion: "What is the definition of the word 'severe'?"; "Exactly who fits the definition of 'severely handicapped'?"; "Can I be a member even though I don't consider my son to be severely disabled?"." Surely we do not want a name that leads to some people feeling excluded! With the renewal form we have been sending out a short survey. We ask What (or who) inspired you to join TASH? What do you like most about TASH? What concerns do you have or changes would you recommend? Responses to the last question very often echo the sentiments of this recent respondent: "Get rid of the name! The language is archaic and devaluing — I thought this was an organization that was against labeling and pigeon holing!"

The discussion of a name change is not new for TASH. In the June, 1994 issue of the Newsletter, Judith Snow was asked to comment on TASH's name. In part, Judith said, "I get suspicious of things that are for someone else. The word 'of' would mean something else." In response to the word "severe", she added, I know it's professional language, but I absolutely hate that word. I see it as a warning sign that someone is trying to have power over me; that our interaction is going to be about disability, not community. With regard to the word "handicaps", it is clear no one likes it. Again, a response from Judith Snow: "I associate charity with the word handicap and a lot of frustration from my own life experience in getting past that barrier."

So, where are we with regard to TASH's name? Some people have felt that with all the changes TASH has been through in recent years, it has been important to maintain our widely recognized acronym. For a couple of years we have tried to be, simply "TASH". Our letterhead no longer contains the name for which T-A-S-H has stood. However, most people I speak with want to know the derivation of the acronym. We even get phone calls from people who find the practice of dropping the full name annoying, "I've looked all over this darn brochure and can't find what TASH stands for anywhere!".

Clearly some people are calling for a name change. Suggestions seem to fall into two broad categories, names that are very general and names that more specifically define who we are and what we do. Some names attempt to maintain the acronym; others move in whole new directions.

Here are some names that have been suggested: The Association (or Alliance) for Social Justice and Human Rights, The Association for the Support of Human Rights, Toward Advocacy, Self-Advocacy and Human Rights, International Disability Equity Alliance (IDEA), Disability Advocacy International, The Disability Action Coalition, The Disability Advocacy Worldwide Network, (DAWN), The Disability Action Network, The Association for Disability Advocacy.

Would you buy: equity, diversity, social justice, inclusion .... I'd like to hear from members on this. If you would like to participate in this discussion, please fax this page back with your responses to the following

1. Do you feel the term "disability" should be included in the name to make clear our areas of concern or is it better to leave it open?

2. Do you think it is important to maintain the well-recognized acronym or should we undertake the effort (and expense!) to change to something new?

3. Do you like any of the names above, any variations on these, or have a suggestion for a new name? THANKS! Please fax this page back to Nancy Weiss at: 410-828-6706 or send me an e-mail at: nweiss@tash.org

WHAT DOES TASH STAND FOR??

Many people want to know what the acronym TASH stands for. Here's a brief history of the organization's names. When TASH was started in 1974, it was called the American Association for the Education of the Severely/Profoundly Handicapped and went by the catchy acronym: AAESPH. In 1980 the name was changed to The Association for the Severely Handicapped, reflecting TASH's broader mission. The name was changed to the Association for Persons with Severe Handicaps in 1983 but the acronym, TASH continued to be used. In 1995, the Board voted to maintain the acronym because it was so widely recognized but to stop using the full name of the organization as it didn't reflect current values and directions. So there you have it!

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TASH (The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

Building communities in which no one is segregated and everyone belongs;

Forging new alliances that embrace diversity;

Advocating for opportunities and rights;

Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

Supporting progressive legislation and litigation; and,

Promoting excellence in services.

EDITOR'S NOTES

This month's issue of the TASH *Newsletter* is anchored by two compelling articles addressing one compelling issue: holding the line against proposed changes to Part B of I.D.E.A.

Liz Healey, newly re-elected to the TASH Board and the parent of a child with significant disabilities, presented powerful testimony last month before both the U.S. Senate and House on the reauthorization of I.D.E.A. Beginning on page 6, Liz provides concrete, first-hand evidence of the successful implementation of I.D.E.A., what works, and how it can work everywhere if the "spirit of the law, and enforcement of the [law's] provisions" are protected and upheld.

Also on the I.D.E.A. front, Marcie Roth, TASH's Director of Governmental Affairs and a number of other key disability rights advocates collaborated on the preparation of a just-released document "Frequently Asked Questions about Part B of the I.D.E.A." (page 15). This comprehensive article details continuing efforts to weaken the legally mandated protections of Part B. Included on Page 20 is a form you can complete and return to TASH, adding your name to the growing list of individuals and organizations who condemn the attempts to minimize the safeguards in place to protect children with disabilities.

The personal perspective of two parents on the effectiveness of I.D.E.A. and what changes to the Act could mean can be found on pages 12 and 28. And John McDonnell responds to a September 1996 TASH *Newsletter* article on high school inclusion with his own viewpoint on the effectiveness of community-based instruction (page 23).

Don't forget the 1997 TASH Conference "Call for Presentations" deadline is **March 31st**! If you missed the application in the January *Newsletter*, contact the TASH office to request the application by fax or visit our web site at http://www.tash.org

— Priscilla Newton, Editor

WHOM DO I CONTACT??

- **For issues of policy, chapter or committee support or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on the conference, including presenter information, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For information on regional workshops, information and referral, technical assistance, or government affairs, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:mroth@tash.org
- **For information on membership, publication/video sales, reprints, and advertising, call:** Priscilla Newton, Director of Member Services, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the newsletter or to make a submission, call:** Priscilla Newton at (410) 828-TASH, Ext. 102.
- **Don't forget to visit TASH's web site at http://www.tash.org**
- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230.

The TASH Newsletter is available on audiocassette for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail: pnewton@tash.org

You Did It - Thanks!!

Thanks to all who donated $5.00, stayed at the Headquarters Hotel, or flew on the official TASH airline for the 1996 TASH Conference. Your efforts helped over 50 parents and self-advocates attend the conference from all over the United States and from as far away as England. Here are some reflections from those who benefited from your generosity and assistance:

> "Excellent Conference - thanks to all who had a part in bringing it about."
>
> "...This turned out to be the most rewarding experience and information sharing opportunity I have had in a long time. I'm encouraging membership in TASH because of the valuable information you supply."
>
> "I made some excellent contacts who are now providing me with information to advocate for my young daughter.. and I think I've made a friend for life."
>
> "Thanks for the accommodations that enabled me to co-present...I attended many other sessions and it was truly a great experience."
>
> "Thanks for the help with costs - I want to attend in '97 in Boston and am starting to raise funds now!"

Let's Do It Again In Boston - SEE YOU THERE!

1997 TASH Conference "We the People, ALL the People"
Sheraton Boston Hotel and Towers • December 10-13, 1997

For a Call for Presentations form or more information ,
call 410-828-8274 or check out our website: http://www.tash.org

The TASH Publications Operating Committee is looking for new members!

The Publications Operating Committee is seeking to expand its membership. The Committee reviews works for publications, contributes to policy decisions relating to TASH publications, and participates in the development of new products and publications. There is interest in establishing a diverse committee membership that is representative of the breadth of interests within TASH.

The Committee meets annually, in person, at the national conference and several times a year by phone. If you are interested in participating on this committee, please call Nancy Weiss at (410) 828-8274, ext. 101 or send an e-mail to nweiss@tash.org. Everyone is welcome!

GRADUATE PROGRAMS IN
MODERATE & SEVERE DISABILITIES

The University of Illinois offers innovative master's and doctoral programs with an emphasis on collaboration to facilitate inclusion of students with moderate and severe disabilities in general education classrooms. At the master's level, the teacher certification program is designed to prepare teachers with expertise in severe disabilities who are skilled collaborators. In addition to the collaborative teacher education program, opportunities are available in the Vocational Coordinator, Community Service Provider, and Research Practitioner master's degree programs. Programs at the doctoral level are designed individually to reflect the interests and experiences of each student.

Applications for graduate students (M.S. and Ph.D.) in the Moderate and Severe Disabilities Personnel Preparation Program for the '97-'98 school year are being accepted now. For more information regarding these programs or about opportunities for individualized doctoral study, minority scholarships and assistance, or financial aid information contact Adelle Renzaglia, Ph.D.; Jim Halle, Ph.D.; or Janis Chadsey-Rusch, Ph.D.; Department of Special Education; 288 Education Building; 1310 South Sixth Street; Champaign, IL 61820; phone (217) 333-0260.

DEPARTMENT OF SPECIAL EDUCATION

UNIVERSITY OF ILLINOIS

Testimony of
ELISABETH T. HEALEY
before the U. S. House Subcommittee on Early Childhood, Youth and Families on the Individuals with Disabilities Education Act

Liz Healey, Executive Committee Chair of the TASH Board, submitted the following testimony on IDEA before the House on January 29, 1997.

Thank you for this opportunity to testify before the House Subcommittee on Early Childhood, Youth, and Families on H.R. 5: The IDEA Improvement Act of 1997. My name is Elisabeth Healey. I am an elected School Board member from the City of Pittsburgh, Pennsylvania, a city of 340,000. This is an unpaid position. I am serving my second term on the Board, and I am the past president of the Board. I was elected president unanimously by my fellow board members. In 1995 I was reelected to the Board without opposition.

I am the Co-Chair of the Pennsylvania State Transition Coordinating Council, an interagency body charged with recommending and advocating for better coordination between state agencies to prepare students with disabilities for adult life.

I am on the Board of Pennsylvania Protection and Advocacy, and on the Board of TASH.

I am also the parent of two children who attend the Pittsburgh Public Schools. My daughter has significant disabilities, and attends Taylor Allderdice High School, our neighborhood high school. Last year Allderdice was chosen as a national Blue Ribbon School, I believe in part because it is a school where the faculty and administration have worked hard to provide all students access to challenging curriculum, including students with disabilities. My son is an eighth grader at Sterrett Classical Academy, a magnet program.

It has not been easy to be this involved in public policy making, to continue to work, and meet the demands of my children and care for my daughter who, because of her significant disabilities, requires a great deal of support to stay healthy. I have been very fortunate to have the support of my husband, and we both constantly juggle our schedules so that one of us is home after regular working hours to care for our daughter. I appreciate that you will hear from very few school board members and families raising children with disabilities. Our family shares common experiences with a great many families who are also struggling to create a positive, promising future for their children with disabilities.

I have a unique perspective, both as a public policy maker charged first and foremost with ensuring that all children receive an education which prepares them for citizenship in our democracy, and as a parent of a child with a disability who has experienced IDEA first hand. I would like to look at the effects of the law on our comprehensive education system, and not just look at special education in isolation.

First, some background on Pittsburgh. We are an urban district, one of the twenty largest urban districts in the United States. The Pittsburgh Public Schools have an enrollment of 40,000 students. 54% of our total enrollment are African American students, and 63.4% qualify for free or reduced price lunch. 5,065 students receive special education services under the IDEA or 12.7% of our total enrollment. Currently 57% of students in special education are African American and the Pittsburgh Public Schools have been working hard on the over-representation of minority children.

By category this breaks down to:

	% of Special Enrollment	% of Total Education Students
Specific Learning Disability	34.4%	4.4%
Mental Retardation	18.6%	2.4%
Serious Emotional Disturbance	11.4%	1.4%
Speech and Language Impairment	29.5%	3.7%

All other categories are less than one per cent of the total enrollment. Mental retardation and serious emotional disturbance are the categories where we continue to have over representation of African Americans.

The Pittsburgh Public Schools have been involved in school restructuring since 1991 when we became part of a national consortium of school districts who were awarded a New American Schools Development Corporation grant. The focus of our efforts have been to align curriculum, instruction, and assessment, to move to site-based management with shared decision making with parents, community, and schools, and to develop a new accountability system that includes all stakeholders. We are a standards driven district and a participant in the National New Standards Project.

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Representative Goodling, in his statement to the House when he introduced the IDEA Improvement Act of 1997, listed the following goals in the reauthorization process:

- Expecting students with disabilities to perform to the same high standards, to the maximum extent possible, as all other students by ensuring access to the general education curriculum and emphasizing basic academics;
- providing funds for training for general education teachers and letting local schools decide what priorities are most important for in-service training;
- changing the funding formula so that the funding is placement neutral with no incentive to place students in expensive segregated settings and no bounty for over referring to special education;
- using mediation to reduce due process and litigation; and
- taking a get tough approach with students who commit crimes to make schools safer. I understand that these reforms are designed to respond to horror stories that you have heard from your constituents about abuses of special education. I would like to examine each of these issues by looking at how we have tackled these problems in Pittsburgh, and by reflecting on our results. Our experience with trying to more fully implement the current law through a system change process has been dramatic. I urge you not to rush to respond to anecdotes, but to examine the data and form a more balanced picture. **IDEA does not need to be overhauled. Districts need to work to more fully implement the spirit of the original law.**

WHAT IS WORKING

IDEA is a good law that is working. It has provided access to education to millions of children who, prior to 1976, had systematically been excluded from public schools.

My experience has shown me that 1) the IDEA has been a vehicle for system change and school reform designed to provide access to meaningful curriculum, 2) that we can raise standards for all students including students with disabilities within the framework of the law, 3) that good special education services do not have to be expensive, 4) that we need to do more to use positive behavioral approaches so that students can succeed in school environments, and 5) that students with disabilities should not be used as scapegoats and be blamed for the discipline problems that challenge all schools.

Our school district has accomplished significant systems change working within the framework of the current law. **We can improve outcomes for students, make our schools safer, reduce costs, and due process proceedings without changing Part B of the IDEA.** The implementation of IDEA is compatible with school reform and the call for high standards.

IDEA HAS CREATED SCHOOL REFORM, HIGH STANDARDS, AND SYSTEMS CHANGE.

There is clear statutory support for educating children with disabilities in general education classrooms. See H.R. 5: Section 601(c) Findings (5)(C)...that special education can become a service for such children rather than a place where they are sent; and Section 612(a)(4)(A) To the maximum extent appropriate (i) children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and (ii) special classes, separate schooling or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child means that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

Use of Discretionary Funds: A Vehicle for Systems Change

Now a look at what the Pittsburgh Public Schools have accomplished under the IDEA. With the help of federal discretionary grants through the IDEA our special education services have gone through a sweeping systems change in the last five years. Key to this success is the fact that Pittsburgh was awarded a grant directly to the school district, unlike the typical practice of awarding these funds to research based university programs that come into school districts and work from the outside. When funding is provided to institutions outside the school district, the resultant changes can be peripheral, cursory, isolated and non-systematic. By design, **we unified the special education administration with the rest of the school system administration because we believed that the slogan of school reform to create a system where all kids can learn to high standards was meaningless if we exempted certain groups of kids such as students with disabilities from that expectation.** We were awarded $5,000 the first year and $11,000 the second year through the Pennsylvania System Change Project funded with IDEA funds. These are relatively small sums to a district with an annual budget of $390 million for basic education, yet we have leveraged the funds to create lasting changes that continue to grow through a ripple effect.

We no longer wanted teachers to use a referral to special education as a way for teachers to get certain students out of their classrooms. We wanted to encourage students with disabilities to be educated in general education classrooms with assistance, instead of in separate classrooms. Most school districts had a history of creating segregated settings to provide education to students covered by P.L. 94-142 instead of supporting students with disabilities in general education classrooms which was clearly the intent of the original framers of the law. Additionally, Pennsylvania like many other states provided a financial incentive to school districts by making it possible for districts to draw down more state funds for more expensive segregated placements.

The first year we began working to support students with disabilities to participate in the general education environment in 3 schools. Students with disabilities did not typically attend the same school as other children from their same neighborhood. Most were taught in self-contained classes located in other buildings. Just 5 years later we are serving all children who need learning support in the school they would otherwise attend if not identified as having a disability. That is in all of our 55 elementary schools, 17 middle schools, and 11 high schools. A key piece of this transformation was again

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made possible through an IDEA discretionary grant. Through a second grant we started our MOSAIC program which serves preschoolers with disabilities within regular preschool programs with a three year IDEA discretionary grant of about $500,000. Before the MOSAIC program, 98% of all preschoolers with disabilities were served in segregated programs serving only children with disabilities. Now these numbers have nearly reversed themselves. 80% of all preschoolers receive their early intervention services in inclusive settings, and only 20% in segregated settings. As these children have transitioned into school age programs, their parents expect that they should continue to go to school with their non-disabled peers. This has created a healthy tension on school-age programs to that children who have been well-served in inclusive preschools can receive parallel high-quality inclusive supports in kindergarten.

As a result of these two IDEA grants this is the first school year that all elementary school age children with disabilities who need learning support attend the same school their neighbors attend. In the first year this has saved the district almost $ 1 million in transportation costs. Additionally, this has created satisfied costumers. This fall when a study was done at two elementary schools asking students with disabilities whether they would like to return to their old school or old special education classes, without a single exception they said NO!

The use of IDEA discretionary funds has created sweeping systems change, built our internal capacity to serve diverse learners, and resulted in a cost savings in transportation.

Another, more subtle part of this systems change process has been that the special education services have become much more family centered, implementing the parent partnership envisioned in Part B. That means that staff listen more carefully to the hopes and dreams of families for their children with disabilities, and hear families' worst fears. Together they work out programs that are responsive to families' concerns, instead of the old paradigm where the professionals know best. This old paradigm was built on low expectations for students with disabilities, and the belief that they would be happiest with their own kind. These patronizing attitudes had toxic results for kids. They were taught less at a slower pace with no hope of ever being able to go on to higher education or hold responsible jobs.

Due Process

A serendipitous benefit of this family centered inclusive approach to providing special education supports and services has been that the number of due process hearings has plummeted. Unlike reports from some other urban districts of an explosion in the number of due process hearings with resultant high costs, last year there was only one due process hearing, and one special education mediation in the entire school district! [illegible]

High Standards

Our task now is to move beyond the access to education that IDEA has provided, to ensuring that the special education programs provide meaningful benefit. When we look at the outcomes for students with disabilities nationally we can see that there is still much work to be done. In Pittsburgh, about 50% of students with serious emotional disturbance drop out of school before graduation, the same as the national average. Nationally, 38% of students with disabilities drop out of school before graduation. Of our students with disabilities who remain in school and graduate, 11% are still unemployed six months after graduation. Nationally, the unemployment rate for adults with disabilities is over 80%.

In Pittsburgh we are examining what would provide meaningful benefit to students with disabilities by merging our school reform efforts with our progress toward educating students in the least restrictive environment - general education settings. Special educators have participated in the development of new curriculum standards and the development of new forms of assessment designed to measure student performance of these new standards. Our experience has shown us that when we include students with disabilities in regular education classrooms, insuring their access to least restrictive environment, everyone benefits. [illegible]. Schools in urban environments are serving a very diverse population of students. Teachers are changing their teaching techniques to meet high standards for all.

Two years ago, the staff at Allderdice High School began teaching algebra and biology to students with disabilities who previously had not been given the opportunity to take these gatekeeper courses. They included these students in regular education classes and began team teaching, pairing the regular subject teacher with a special education teacher. The results were dramatic. The special education students with this support succeeded in these classes previously thought to be too difficult for them, and when we compare the class averages of the regular classes and those that provided more support to all students through team teaching, these inclusion classes had higher class averages. This demonstrates that when we provide appropriate support to students with disabilities everyone benefits and shoots down the myth that inclusion hurts the other kids in the classroom, and that inclusion really only works in elementary schools before students have to tackle more demanding curriculum. This inclusion model at Allderdice has been extended to chemistry and geometry.

When some of the regular education teachers who participated in team teaching were asked what they thought about having students with disabilities in their classes, they responded most students with disabilities experienced the advantages of a broader understanding of certain topics, the increased activity of larger classes, the ability to compete at the same level as other students, and the satisfaction in knowing their ideas and answers are equally accepted. In fact, many teachers think it is very successful. Some of the special education students are

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doing better in geometry than the other college and career prep students. The belief is everyone has benefited from this model. These innovations have given real meaning to the "All kids can learn" mantra of school reform.

Part B of the IDEA provides students with disabilities the opportunity to learn to high standards by insuring their right to least restrictive environment. Students cannot learn what they have not been exposed to. By implementing the least restrictive environment students can learn to high standards.

The results of the Pittsburgh Public Schools as a whole demonstrate that when students with disabilities are included in regular education classes with appropriate support, all students do better.

Costs

As we have gone through this systems change effort, **we have found that good special education does not have to be expensive.** Costs of special education have been contained because:

- we have saved money on the cost of transportation,
- we have had a decrease in the cost of litigation through due process,
- we have saved staff costs because of a realignment of roles.

Bussing kids to special classes out of their communities was expensive, and we were spending money on transportation that could be used for instruction. We are using staff differently now as consultants and technical assistants to classroom teachers. Under the old paradigm great importance was given to one-on-one time with specialists - occupational therapists, physical therapists and others. Parents were led to believe that these specialists, much like the laying on of hands of old time faith healers, had special powers. We now know that it is whether or not there are opportunities to practice new skills throughout the day that is far more important. We are teaching teachers and classroom assistants to carry out the activities recommended by specialists through the school day, not just when the specialist is there to do it directly.

Take my daughters' program as a case in point. She needs stimulation to remain alert. She needs to be touched by caring people and given opportunities to interact with others. She used to be transported to a special education center across town in a class of 7 students with a teacher and two aides at a cost of $48,000 a year. She got one-on-one time with the teacher or an aide periodically throughout the day. The rest of the time was down time. None of the other students talked or could move to interact with her. Now she goes to the high school which is about 3 blocks from our home. She is immersed in the activity of other students throughout the day. People talk to her, touch her, and she moves from room to room experiencing a rich and varied environment full of stimulation. She does not have to wait her turn anymore. This costs $14,000 a year for her assistant who spends part of her time helping other students. It costs $34,000 less to educate my daughter in a rich, stimulating environment.

These expensive segregated settings have another negative consequence for kids. More time spent with professionals in one-on-one work, the more likely it is that the individual will be dependent as an adult, and the less likely that the individual will be served by the adult service system because of the high cost of this type of service. Segregation prepares students for adult lives in more custodial care settings like sheltered workshops, institutions and large congregate living facilities.

I am concerned that my daughter will have a place in the fabric of our community. For other kids, schools perform the function of preparing them to live and work in our communities. Schools need to create those possibilities for children like my daughter, too.

POSITIVE BEHAVIORAL APPROACHES

The field of positive behavioral approaches has demonstrated amazing results with children and adults who have challenging behaviors. This year the Pittsburgh Public Schools hired a full time behavior specialist to work with teachers in general education settings and with special educators to develop behavior plans using positive behavioral approaches so that students are able to function in school. His job is to teach educators how to assess what approaches would work for different kids, and then provide educators the technical assistance they need to become skilled in using positive approaches. The old negative reinforcements and token systems for rewarding good behavior are not very effective. And yet they are the most common methods found in IEPs for students who have challenging behaviors. This poor man is in great demand. We could use several behavioral specialists to meet the needs of schools. This is an important area where targeted discretionary grants to states and school districts could make a dramatic difference in providing a meaningful education for students so they are able to function in school and the community.

We cannot ignore the many successes of positive behavior supports being effectively delivered to students who are gaining the ability to function appropriately in the real world. Knowing it is possible to achieve success in this area, we cannot settle for anything less. Use discretionary grants to create systems change utilizing what we already know is working and to further improve the skills of school teams to achieve even greater results.

DISCIPLINE

Safety in public schools is a very real problem. Although the crime rate has dropped in the past year, the number of crimes committed by youth continues to increase. There are over 400 adjudicated youth enrolled in the Pittsburgh Public Schools based on reports we receive from Juvenile Court. Children are being raised in a climate where violence is commonplace. They see it on TV, and they experience it in their own neighborhoods. Our youth are becoming much more likely to lash out when challenged, and social custom no longer sanctions the bully for his/her behavior. We are far more likely to try to stay out of the way of a threatening individual, for fear that challenging someone will bring retaliation. Who knows, they may have a gun. It is not surprising, then, that these behaviors are on the rise in our schools.

Some education organizations would have you believe that special education students are the root cause of lack of discipline in schools. They are responding to complaints from their constituen-

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cies. I know from my experience on the School Board that people rarely call to tell me wonderful stories of things that are working well. I get calls from constituents when there are problems. I suspect that the opinions of these organizations are based only on complaints, and you have probably heard anecdotal reports of the very worst cases. But data from the Pittsburgh Public Schools does not bear out this myth that the kids with disabilities are the problem. The actual facts are that **the suspension rate for students with disabilities is lower than the suspension rate for the rest of our enrollment. 1.1% of all special education students are involved in discipline proceedings annually, as compared to 2.0% of the total enrollment** .

Some of these same organizations talk of fairness, and that IDEA gives special protection to students with disabilities. But we need to look at the facts. Last year the Pittsburgh Public Schools expelled from our total enrollment less than a dozen students for one year or more. All of these students were past the age of compulsory attendance. Some enrolled in private schools. Some we offered standard evening school, and they chose not to go. There were 180 students expelled for over 10 days or more and transferred to an alternative program because of weapons, drugs, or an assault on staff or another student. When a student commits a crime our school district presses charges and has the student arrested.

As a Board, we do not believe that it is in the best interest of the student or the community to put a youth out on the street with little hope of turning their lives around. In the vast majority of cases we do not cease all education services. We place these students in alternative settings designed to provide intensive academic support, and use positive approaches involving students in different and more constructive activities, both in school and during non-school hours. As a matter of public policy, cessation of services to students who bring drugs or weapons to school makes no sense whether they have a disability or not. It is extremely unlikely that a youth who is involved in drugs or weapons who is expelled from school for one year will ever return to school. Putting these youth on the street with no help to turn their lives around does not make sense and makes our communities less safe for everyone. They will most likely wind up in the criminal justice system, and then no one wins.

Educators argue that they cannot remove a special education student from their current placement because of the stay put provision. But they do have a remedy. They can go before a judge and ask for permission to remove a student from his/her educational placement over the objections of the parents. School administrators are reluctant to do this, and this is true in my own district. But this very reluctance assures that seeking this removal will not be commonplace, and there must be strong reason to remove a student. It should encourage school districts to try other strategies first. Sadly, too few schools districts have skilled behavior specialists on staff trained in positive behavioral approaches. If the only tool you have in your tool box is a hammer than everything looks like a nail. Much like the Queen of Hearts in Alice in Wonderland who ordered Off with their heads! when ever anyone upset her, our schools are too quick to punish without looking to see how to modify the environment or what types of support could prevent the problem behaviors. I think that changing the law to permit placing students with disabilities in alternative settings because the school thinks they may be likely to cause harm will result in trampling on the Least Restrictive Environment preference in the law, and again reward teachers by getting rid of students they find hard to teach, and undoing what you are attempting to accomplish by the removal of the funding preference for segregated settings.

RECOMMENDATIONS: DO NOT REOPEN PART B

Part B provides all of the above mentioned benefits. We can more fully implement it and provide the additional benefit of positive behavioral approaches without changing Part B.

Our school district has used the IDEA to improve services for students with disabilities. I would like to recommend several ways to improve results for students with disabilities. I would: 1) raise teacher expectations through accountability, 2) require that evaluations produce meaningful instructional information, not just a label, 3) encourage positive behavioral approaches through discretionary grants, 4) more actively enforce the existing provisions of the law, and 5) give discretionary grants directly to school districts to produce meaningful, lasting changes. These changes can be made without opening up Part B.

Raise Teacher Expectations Through Accountability

I would hold educators accountable for providing meaningful instruction to all children to raise the low expectations some educators have for children with disabilities. **Research has shown that attitudes follow behavior. If you can compel a person to act in the desired way, then attitudes will change to conform to the new behaviors. So if we make teacher ratings dependent on student performance, there will be great pressure to change their behaviors.** Currently, these low expectations lead to withholding from kids instruction that will prepare them to hold jobs and live in the community as adults. Low expectations are robbing our children of their future. Including children with disabilities in assessments may be the best way we have of changing teacher behavior, because we can then assess teacher competence based on the progress of their students.

In Pittsburgh, as we are developing standards, we are identifying key concepts and competencies we want all children to have, and are developing new forms of assessments to measure student performance against these standards. Careful planning is being done to describe ways that students with disabilities can demonstrate these same competencies.

Nationally there is a debate about whether to test only those kids in regular education classes, or to test everybody. We should not decide which students to exclude from assessments. I believe that all students should have to participate in these assessments. This will be the most powerful way to change teacher behavior and expectations. Every student's performance should count. This can be done without opening Part B.

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Evaluation

Every student who receives services under the IDEA must be evaluated initially to determine that they are eligible for special education services, and then reevaluated every three years to determine that they continue to be eligible. Currently, in most cases the evaluation consists of putting a label on a child, and then periodically reconfirming that they still should have that label. **I think that to use evaluation simply to label kids is a waste of money. What is meaningful is to use evaluations to determine what types of instruction and supports will facilitate learning for students.** This is rarely done and most school psychologists are skilled at administering standardized tests to only confirm labels. I did not need a battery of tests to tell me that my daughter cannot control her body, cannot see, and will be able to learn only very simple things. What is important is how to teach her to use the gifts that she has.

I would love to see targeted discretionary grants to do this retraining of professionals to be able to produce meaningful information in evaluations that will guide teachers in determining most effective ways to teach children with disabilities, not just label kids. This can be done without opening Part B.

Positive Behavioral Approaches

It has been shown that teaching teachers to support children with disabilities in regular classrooms benefit all students because teachers begin to be better able to identify why students are having difficulty learning, and to use more varied and effective strategies. The same holds true for behavior. Training teachers to use positive behavioral approaches will help students with disabilities, and it will also help those other students whose behavior is a problem in school. This can be done without opening Part B.

Enforcement

Through federal monitorings done to evaluate compliance with the IDEA some constructive changes have occurred in our district. We were forced to reexamine our suspension policy, and to begin transition planning prior to the last year of school and to involve appropriate adult agencies in the planning process early on. This has strengthened our programs. This can be done without opening Part B.

Award Discretionary Grants Directly to School Districts

As I explained earlier, the federal government gets far more benefit in terms of lasting change when targeted discretionary grants are awarded directly to school districts rather than to research based university programs. There is more ownership of the change process, the changes are more likely to be sustained, and these changes have a ripple effect spreading their influence far beyond the grant time period. Increase funds for in-service training to give teachers skills necessary to meet the needs of diverse learners and to create learning environments where all students can learn. Again, this can be done without opening Part B.

Shared Funding Responsibility for Special Education Services

Finally, a word of caution about hopes of using Medicaid to fund supports and services for students with disability. In Pennsylvania, the Department of Welfare has voluntary options for Medicaid recipients to join managed health care plans administered by private insurance companies. It is anticipated that soon it will become mandatory. The Pittsburgh School Districts have many health partnerships with local hospitals that operate school based health clinics. The hospitals had anticipated that they could bill Medicaid to recoup part of the cost of operating these clinics. However, these managed care plans do not permit recipients to receive services from out-of-network providers, which means unless the clinic happens to be the student's primary care physician, the managed care plan will not pay for their services. The same could happen to the school district when it tries to bill these managed care plans for services rendered by the district. The other option is to have each managed care plan send in their own therapists. This would be a coordination nightmare in a district of our size to ensure good communication between therapist and teacher, with hundreds of outsiders coming in to serve only one or two students each.

CONCLUSION

PL 94-142 has worked to provide access to education. The challenge we now have is to shape those special education supports and services to provide a meaningful education that prepares kids to be full participating members of our communities, able to work at real jobs, live where they choose, and have relationships with others. I believe that the basic tenets of the law do not hamper accomplishing this task, and in fact, I believe that when used in the way it was intended, Part B supports these goals. I do not support opening up Part B for amendments. It is already permanently authorized. I believe that the criticisms of IDEA are overstated, based on anecdotes, and cannot be supported in fact. Because of a few horror stories, you are being asked to dismantle the basic rights embodied in the IDEA for all children with disabilities. When schools do things right, problems go away. When schools really listen to families' dreams for their children and understand their worst fears, programs can be designed that are highly effective, are not extraordinarily costly, and few parents resort to due process. Students with disabilities are not the source of lack of discipline in schools, and with the use of positive behavioral supports students will be more able to function in the school environment and in the community, and everyone benefits from the result. Removing students from general education classrooms denies them access to the general education curriculum and the opportunity to perform to high standards. Students cannot learn what they have not been exposed to. Denying an education to a child will have enormous negative consequences for us all.

With full implementation of the spirit of the law, and enforcement of the provisions of the law, I believe that we have the tools we need to fulfill the promise of preparing all children to perform to high standards and to be responsible, contributing members of our democracy.

India's Story: How IDEA Protected Her Rights

BY BARBARA AND M. WAYNE DYER

There is a temptation for teachers and other professionals to judge people in terms of their behavior and outward appearance. It is all too seldom that we see through the apparent and visible which mask the person who has been wounded by rejection and segregation. We fail to realize that much of behavior and acting out is not inherent to disability, but is learned as a response to being not truly loved and accepted as a person. Masks are worn only as long as they are needed. Only genuine acceptance and sense of belonging will lure the rejected and supposedly inferior out from behind the mask. Often we do not hear the cry in pain and the need to be loved. Most behaviors of persons with disabilities are defensive protection from further hurt and from the pain of rejection. For integration to really work, we must see through the disability to the person. Concentrating on the handicap will only reinforce exclusion and self-containment. There is a lonely void in the lives of persons with disabilities that can only be filled with acceptance, welcoming and belonging. In schools with inclusive communities, we focus on the premise that each belongs in that living reality and we discover the truth of the dignity of each person.

From Reflections of Inclusive Education by Patrick Mackin

India is a 10-year old fourth grader at Fairmont Elementary School in Johnson City, Tennessee. India has Down Syndrome, which serves to be more of a challenge than a roadblock because India has always functioned more like the rest of us than otherwise. As long as she has her family or an age appropriate peer to emulate, she gets along fine.

India has always been placed in an inclusive setting throughout her educational experience. Such was the case again In August 1995, when India joined her classmates in a regular class setting. Within the first three weeks of the school year, her teacher and her assistant reported that everything was progressing impressively. Everyone seemed encouraged.

In mid-September, we became aware of some controversy concerning India. One evening we received a phone call from an attorney's wife, whose child is in India's class and also on the same swim team with our other children. She said they had to make a tough decision about their child's school placement and wanted us to know first hand before we heard from others that they had requested their child be moved to another classroom. She explained that their child was particularly sensitive to the issue of special needs and that she was so overcome with concern about India's treatment, that she talked about it incessantly, was unable to sleep and was making bad grades.

We said we understood and were sorry they were experiencing a difficult time. We told them had we known, we would have been glad to help in any way we could. A few days later, another child's mother stopped us as we were leaving the soccer field and showered us with all kinds of accusations about India attacking her son and how all the children had begun to hate India and were no longer tolerant of her. Throughout these reports, school personnel claimed to be unaware of these issues and insisted that except for sporadic episodes of harmless infractions, all was still under control.

By the first of October, everything seemed to have escalated to a new level. We learned through a newspaper article that the mother of a child in India's class had spoken during a school board meeting about the concern she had for her daughter's safety while at school. She went on to state that our daughter had abused and assaulted her daughter and that she had spoken to school officials about having India removed, to no avail. The next day, there was another newspaper article and several radio reports in response to a visit from Senator Frist at a "town meeting" where this same family was represented by the father, who spoke about people talking responsibility for their children's actions.

The next morning this family telephoned the principal of the school to say their child had suffered spinal injury during an incident that the teacher and assistant characterized as a non-incident and which, in fact, was never reported at all by the child on the day the incident allegedly occurred. They said they expected the school system to be responsible for the medical expenses ($250) already incurred and any additional expenses thereafter. (To-date, these expenses have never been documented or submitted for reimbursement.)

Around this time, this same family removed their child to a private school. A few days later, a mother and child from the class volunteered the information to us that they were not involved in "what everyone was doing to us" and that the family involved in these earlier incidents had been calling all of the other parents trying to get them to join in their endeavor. This classmate of India's also stated that the child of this family had been harassing India and "pushing her buttons" to get India to misbehave, as well as she and another child spitting in their own food and reporting to school personnel that India was responsible. India's friend also reported that this child told India that "she didn't deserve to live in this lifetime." The whole scenario seemed so bizarre and contradictory. At this point, however, it began to take still a different twist.

On October 5th, the superintendent of schools received a three page letter from an attorney/parent whose child had already been given alternate placement out of India's classroom. The letter was on the attorney's official legal firm letterhead. This gave the appearance that the attorney might be representing someone else as he, indeed, mentioned details of the position of the family who claimed spinal injury, but the letter also discussed his own family's position. Generally, it was a horrid expose of libelous innuendo which was very inflammatory and injurious of the reputation of our child and family.

Normal, typical behaviors of third, fourth and fifth grade children found in our child with Down Syndrome were exploited and sensationalized. A friendly plea to "scoot over beside me", accompanied by a gestural pull of the elbow was diverted into long-term medical implications and possibly even eventual disability of a child for reasons of prejudice and monetary gain. In addition, there were obvious leaks from the educational system about our child's multidisciplinary team decisions, her educational program and her Individualized Education Plan, which threaten the perception of the general public regarding the success of the principles of least restrictive environment (inclusion) and endanger a child's right to placement with his/her typically developing peers. These are the kind of people who look for any excuse to justify their bigoted view of who has the right to exist and who doesn't. Children with disabilities, such as ours, are very vulnerable to the prejudiced and discriminatory acts of people who, to further their own agenda, would indict defenseless, voiceless children.

The receipt of the letter from the attorney/parent and the allegation of spinal injury by the other parent set off a chain reaction of events. The first reaction was by the school system, which was understandably "rattled" at being "put on notice" by the receipt of the letter from the attorney/parent. They tried to convince us of the need to temporarily mandate a "cooling off" period of three weeks wherein India would be moved to the resource room with no contact with her peers. Suddenly we found ourselves involved in a series of ongoing meetings, the substance of which included the threat that if we didn't agree to India's "alternative placement", she would be out of school, or suspended if she as much as touched another child. For our part, we stated we intended to file due process which would include the "stay put" provision until resolution.

Finally, we were able to compromise on a plan which involved less time in the regular setting but not as little as had originally been proposed. We felt very strongly that this whole idea involved unfounded punitive action since our child had done nothing wrong except exist. It would send the wrong message to her peers and everyone else if we were to agree with the proposal in total.

Other by-products of the situation included one of these parents going into public forums, including three school board meetings, a federal OSEP compliance meeting, a TV and radio interview, and numerous newspaper articles, and speaking at length about how our child was abusive, and assaulted others with no provocation. Other parents tried to get a juvenile petition filed against India in court, reported us to Social Services, went to the District Attorney's office, the state attorney for special education, and the state special education director all in an effort to have India removed from the regular education setting. Thankfully, these efforts have failed.

Because of the current provisions in IDEA, all of the above attempts failed...India was protected!

After many months, we are still dealing with the fallout which ensued, as it seems that once someone creates the perception that something is true, there are others who continue to try to validate its existence.

We plea with you to serve yourself and the communities that you represent to let it be known that the proposed changes in the reauthorization of IDEA will effectively remove children with disabilities from regular classrooms in the public schools and then be accountable by exercising your rights through your vote against these atrocious inequities proposed against those who don't have a voice or a vote! Allowing school officials the opportunity to deny education to individuals with special needs for frivolous charges by

. . . removing them from their current placement takes away the proximity of those with and without differences and ends the possibility of developing a "circle of friends" and the elimination of fear of the unknown which fuels myths about those with disabilities.

Children like India deserve the opportunity to learn, work and play alongside their age appropriate peers. Our children have much to gain but they also have much to give in the teaching of understanding, acceptance, tolerance, and celebration of diversity. We have concern for our citizens who can't always speak for themselves and who are terribly vulnerable to the exploitation of others who have hidden agendas.

Update:

In the months since the Fall of 1995, much time was spent just maintaining placement, composure, and some order of security and stability for India and her classmates until the end of the school year. We, as parents, watched very closely to make sure there were no possibilities of other problems. This meant that our goal of increased independence for India and a greater measure of movement, just like "everyone else," was delayed again because of the need to micromanage. The assistant was also rescheduled to be there at all times.

The Spring IEP team looked very closely at placement for the fifth grade to ensure a good match in order to increase the chances for success. This issue of a "match" had always been important to us but not necessarily to school officials. We felt this was a good first step. We also met with the superintendent and requested a system-wide person who could serve as an "inclusion specialist" to assist all teachers who deal with inclusion, as far as best practices and methods in modification of curricula. We also requested the choice of a multi-age classroom (3rd, 4th, and 5th) for parents and children at this level. Both requests were denied.

The week before the current school term started, we found out that all of the families who had been in opposition, except the one who moved, had requested the same teacher placement as India's. We did not respond and moved forward to find that this teacher is truly a gift and is dedicated to insure success!! She has developed meaningful curricula which parallels the regular class and is unconditionally India's ally, as she sincerely respects and loves her.

Entering the second half of the fifth grade, we can report that everything is great, even in spite of an allegation a few weeks ago of a "stabbing" (as India held the flagpole for the pledge, the end got too close to a young person). When the parent came forth to complain, this teacher simply laughed and stated that she felt it was an innocent incident but had checked for injury only to find none. The teacher then went on to explain to this oppositional parent that India is a permanent member of this classroom family. The state complaint which we made (Fall 1995) came back as a breach of confidentiality by the system which allowed certain families to perform bigoted acts, a rap on the hand of the system. It just proves that when there's leadership and the right things in place, things work quite nicely!

FLORIDA TASH CONFERENCE

CREATING COMMUNITY: FLORIDA'S SUCCESS

Florida Mental Health Institute, University of South Florida
Westside Conference Center
Tampa, Florida

Saturday, March 15, 1997
9:00 AM - 4:30 PM

The Florida Chapter of TASH is pleased to present a conference for persons with disabilities, their families, educators, and service providers. Al Coneluci, Ph.D. of United Cerebral Palsy, Pittsburgh will deliver a Keynote address on Interdependence, and concurrent sessions will be given by self-advocates, practitioners, and family members to highlight success stories in transition programs, supported employment, school inclusion, and supported living.

For more information, contact:
Elizabeth DeSousa, 8704 Minnow Cr., Tallahassee, Florida 32312
(904) 668-8678

VIRGINIA COMMONWEALTH UNIVERSITY REHABILITATION RESEARCH AND TRAINING CENTER ON SUPPORTED EMPLOYMENT

Title: Supported Employment Handbook: A Customer-Driven Approach for Persons with Significant Disabilities

Edited by: Valerie Brooke, Katherine J. Inge, Amy Armstrong, and Paul Wehman

The purpose of this manual is to provide a contemporary training resource on implementing supported employment using a customer-driven approach. This is a model that works when the customer directs the process. We must be prepared to support the customers of supported employment to obtain the careers of their choice. - *Paul Wehman*

This comprehensive handbook will provide detailed information and techniques on such topics as:

Organizational Marketing
Developing a Customer Profile
Directing the Job Hunt
Knowing the Job Seeker
Promotional Tools
Crafting the Job Search
Job Accommodation
Job Restructuring
Job Analysis
Task Analysis
Natural Supports
Natural Cues
Instructional Strategies
Self-Management
Job Site Modifications
Assistive technology
Fading From the Job Site
Long Term Supports
Employment Mentors
Funding Support and Services

This handbook can be purchased for $21.95, or to receive more information and a free brochure contact Teri Blankenship at (voice) 804/828-1851, (TDD) 804/828-2494 (fax) 804/828-2193, & (e-mail) tcblanke@saturn.vcu.edu . VCU is an EEO/AA University, if accommodations are needed contact Teri Blankenship.

This paper was prepared for parents, self-advocates and other advocates on key issues pertaining to Part B of the I.D.E.A. and current efforts to weaken safeguards for children with disabilities. Its intended use is to provide a tool for parents and advocates to educate and inform members of Congress and other key state and federal policy makers. The paper has been developed through a cooperative effort by groups and individuals dedicated to preserving the rights of children with disabilities in the I.D.E.A.

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Frequently Asked Questions About Part B of the Individuals with Disabilities Education Act

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A GOOD I.D.E.A.

Keep the Rights, Realize the Promise

PART B ALREADY:

Protects Kids
Protects Schools
Protects Families

Don't Change It
Make It Work

REVISED JANUARY 30, 1997

What is the I.D.E.A.? What are the Various "Parts" and What Do they Do?

The Individuals With Disabilities Education Act (I.D.E.A.) was put into place two decades ago because schools denied access to over one million children with disabilities even though the 14th Amendment to the Constitution guarantees an education. The I.D.E.A. had to be passed in order for schools to recognize that children with disabilities have the same constitutional right to an education as do all children.

When Congress passed the I.D.E.A. they noted that over one million children with disabilities in the United States were being denied an education, that many children who were in schools were not being well educated because their disabilities were undetected, that families were forced to find and pay for educational services outside the public school system, that teachers and other school personnel needed additional training to teach children with disabilities and states and local districts were responsible for educating children with disabilities. Most importantly, Congress stated that "**it is in the national interest that the Federal Government assist State and local efforts to provide programs to meet the educational needs of children with disabilities in order to assure equal protection under the law**".

The nine Parts of the I.D.E.A. are:

Part A) Contains the general provisions of the I.D.E.A. including the Congressional statements of why the law was needed. Established the Office of Special Education and Rehabilitative Services. **Part A is permanently authorized.**

Part B) Contains the obligations of States to provide education for children with disabilities and the requirements for States' participation in the I.D.E.A. Defines the role of the federal government including monitoring and enforcement of the law. Importantly, contains the **procedural safeguards for children with disabilities and their parents** which are currently being threatened. **Part B is permanently authorized**.

Part C) Established regional resource centers. Contains special provisions for children who are deaf-blind, young children with disabilities, children who have severe disabilities, the transition from school to adulthood for young people with disabilities, and children and youth with serious emotional disturbance.

Part D) Contains provisions for the training of personnel for the education of children and youth with disabilities. Established parent training and information centers in the States.

Part E) Contains provisions for research in the education of children and youth with disabilities.

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Part F) Contains provisions for instructional media for individuals with disabilities.

Part G) Contains provisions for assistive technology for individuals with disabilities.

Part H) Contains provisions for the identification and provision of early intervention services for infants and toddlers with disabilities and their families. Establishes the State Interagency Coordinating Councils and contains **procedural safeguards for infants, toddlers and their families.**

Part I) Contains provisions for family support but has not been funded to date.

What Does Permanently Authorized by Congress Mean?

When Congress enacted the I.D.E.A., they recognized the importance of Part B to counter years of educational denial to children with disabilities. **Congress permanently authorized Part B of the I.D.E.A.** to protect children with disabilities from harmful changes such as those proposed in 1996 by the 104th Congress as a result of lobbying from education groups. In its wisdom, the Congress that enacted the I.D.E.A. in 1975 realized the rights of children with disabilities may continue to be challenged in the future. **They did not want the rights of children with disabilities reopened and scrutinized by unfriendly future Congresses.**

They did not want the rights of children with disabilities protected in Part B to be negotiated. They told future Congresses to fund Part B at a level that will assure full implementation and enforcement.

Why is Part B of the I.D.E.A. so important to children with disabilities and why shouldn't it be changed?

Part B of the I.D.E.A. is important because it contains the basic right to a free and appropriate public education in the least restrictive environment for children with disabilities, explains what is required of the public education system and authorizes supplementary funding to the States to assist in educating students with disabilities. It also contains procedural safeguards for children with disabilities and their parents to assure that their educational rights are not diminished, that they are not discriminated against and schools do not deny educational benefits to any child with a disability. Congress found Part B to be necessary after years of denial and discrimination against children with disabilities.

Part B of the I.D.E.A. assures:

- **The Right to a Free and Appropriate Education for all Children with Disabilities**
- **The "Zero Reject" Principle.....every child with disabilities has a right to a free and appropriate education.**
- **Children with disabilities have a right to be educated in the least restrictive environment...... the school and class in which they would be educated if they didn't have disabilities and that children are not removed unless the school can demonstrate the child cannot learn in that environment with the provision of supports.**
- **The right for all children with disabilities to have an education that is individually tailored to meet their unique needs through the development of the Individual Education Program.**
- **The Right for Parents to Examine Their Child's Records.**
- **The Right for Children Whose Parents are not Known to Have Their Rights Protected.**
- **Written Prior Notice to Parents When Schools want to Initiate or Change the Provision of Their Child's Education.**
- **The Right for Parents of Children with Disabilities to be Fully Informed.**
- **The Right for Parents to Complain with Respect to Their Child's Education.**
- **The Right to a Hearing, to be Accompanied by Counsel, to Written Findings of Fact, to Present Evidence and to Reasonable Attorneys Fees When Parents Prevail.**
- **The Right for Students with Disabilities to Stay in Their Current Placement ("Stay Put") When Their Parents Disagree with Proposed Changes in Their Education.**
- **The Right for Parents to Participate in Decisions Made About Their Child's Education.**

Part B of the I.D.E.A. is permanently authorized which means it is not discretionary and should not be subjected to Congressional scrutiny in order to be funded. The Congress that passed Parts A and B of the I.D.E.A. was sending the message to future Congresses that they should fund those parts without amending them.

Has the I.D.E.A. been fully implemented and enforced since its enactment in 1975?

No. Although the I.D.E.A. has resulted in access to the schools for more children with disabilities, full implementation and enforcement have not yet occurred. The Office of Civil Rights has issued findings that schools have failed to identify, locate and evaluate all children with disabilities. The U.S. Department of Education has issued monitoring reports to States which indicate children are not being provided a free and appropriate education in the least restrictive environment. Fifty percent of students with serious emotional disturbances drop out of school before they graduate. Thirty eight percent of all students with disabilities drop out of school before graduation with minority and low-income students at even greater risk. The

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unemployment rate for adults with disabilities is over 80%.

Part B and the discretionary programs in the I.D.E.A. were designed as vehicles to assure all children with disabilities have a free and appropriate education, as well as to provide equal protections under the law. The nation must not retreat from this goal.

Have changes been made to Part B in the past?

Technical changes have been made to update language that after time was not appropriate. For example, the original "handicapped children" was changed to "individuals with disabilities" throughout the I.D.E.A., including Part B. Technical changes do not violate the intent of Congress to permanently safeguard the educational rights of students with disabilities. **Substantive changes have been made only to strengthen and improve Part B and only after years of research and demonstration.** For example, assistive technology was added as a related service when the educational benefit for many children with disabilities became apparent. A requirement for transition planning was added to emphasize the role of education in preparing young adults for full community participation in adulthood and assisting them in obtaining needed adult services and supports.

Since 1975, efforts to weaken the safeguards for children with disabilities have been rejected by Congress. The 104th Congress (1995-96) was the first Congress to seriously attempt to weaken the educational rights of students with disabilities. Although the 104th Congress was not successful, the 105th Congress has introduced the same legislation.

Who is proposing changes to Part B of the I.D.E.A. and why are they proposing them?

The groups who are proposing changes are **the American Association of School Administrators (AASA), the American Federation of Teachers (AFT), the National Association of Elementary School Principals (NAESP), the National Association of Secondary School Principals (NASSP), the National Education Association (NEA) and the National School Board Association (NSBA).** These powerful education groups have based the attack on Part B of the I.D.E.A. on rhetoric and loose anecdotes which assert that children with disabilities are the cause of rising violence in the schools; schools are financially suffering because of "sneak attacks" in the forms of complaints, due process hearings and law suits; parents are financially rewarded for their "sneak attacks"; students with disabilities impair the ability of teachers to teach and general education students to learn; and, generally, promoting ill-will among the general public against children with disabilities through the media.

These groups made their position clear in a joint position paper in 1996 despite the lack of factual data to back up their assertions. In a joint statement in 1996, those groups stated, "Because of school violence, the enormous costs of special education and related services, and greater inclusion, federal special education law is having a greater impact on the rights and needs of non-disabled students.......we urge Congress to balance more carefully the needs of students with disabilities with the needs of all students". Interestingly, their joint efforts to weaken Part B of the I.D.E.A. came on the heels of the American Federation of Teachers' call for "a moratorium on the rush to inclusion".

These powerful groups have used their influence to convince important people in Congress that the entire future of education is threatened by students with disabilities. As a result, both a Senate Bill and a House Bill were introduced in 1996 which would have eliminated the safeguards in Part B. Members of Congress and their staffs informed families that the changes were inevitable. Disability groups were pitted with threats of withholding funding for I.D.E.A. discretionary dollars. When the 104th Congress failed to weaken Part B, the same groups vowed to introduce and pass the same legislation this year.

Is there factual information and data to back up the changes these groups want to make?

Minimal and inadequate information has been used to support the drastic changes these groups want to make to Part B. No factual data have been submitted or even exists. The proponents of "gutting" Part B rely heavily on loose rhetoric and red herrings that depict children with disabilities in violent acts and cite unreasonable/costly educational placements made by school administrators as the norm. They imply that teachers' abilities depend on the absence of children with disabilities in classrooms. To date, there is no persuasive evidence to support these claims.

Ironically, as a result of the I.D.E.A. discretionary programs, there is a large body of promising research and methodology available to schools to assist them in improving the educational outcomes for children with disabilities. The I.D.E.A., as written, requires "state-of-the-art" information and research to be disseminated to teachers. Additionally, educational research indicates children with and without disabilities benefit from being educated together and having access to the same curriculum, teachers are better equipped to teach diverse children than in the past, good education is equivalent with success in adult life for children with and without disabilities, and the cost benefit of a good education for all children is enormous.

What changes are being proposed that will harm children?

Among the harmful changes are:

- **An elimination of the "zero reject" principle and the right to a free and appropriate education.** This would be accomplished by allowing school officials to expel and cease providing an education to students with disabilities for certain offenses including possessing weapons, drugs or engaging in "seriously disruptive behavior". There are procedures in current law that apply to children with

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disabilities who engage in dangerous behaviors while taking into account the special circumstances brought about as a result of the child's disability.

These procedures allow schools the flexibility to respond to dangerous behaviors and make special determinations regarding educational placement but does not allow schools to cease providing an education. This is to prevent a return to the past when children with disabilities were denied an education without legal challenge. The United States Department of Education developed a policy paper in 1995 titled, "Questions and Answers on Disciplining Students with Disabilities" which was widely disseminated to the States and explains how schools can deal with dangerous behaviors in schools.

- **An elimination of the "stay put" provision thus ending parental participation in their child's education.** This would eliminate the right of children with disabilities to remain in their current educational placements (stay put) when their parents disagree with proposed changes in placement. The "stay put" provision is the only recourse parents have when schools decide to send their children with disabilities out-of-school or out-of-district.

- Critically, in addition to the elimination of "stay put", **local school districts will be able to define what constitutes "seriously disruptive behavior" and what "impairs the ability of the regular education teacher to teach".** This is particularly dangerous for children with disabilities who have behaviors and/or movement disorders that are manifestations of their disabilities. Experience has shown that many school personnel believe that all children with diverse learning styles and needs are "disruptive" and should be in alternative places.

- **Eliminate or drastically reduce the requirements that States provide a plan on how they will provide education to children with disabilities and reduce federal monitoring.** The problems that exist with the I.D.E.A. today are related to a lack of adequate implementation, monitoring and enforcement. Even though it's a good law, many students with disabilities are still denied access to the school doors and full participation in the educational curriculum. Families still must struggle against discrimination to assure their children receive an appropriate education. The I.D.E.A. is a good law that has never enjoyed full implementation and accountability.

- **Deny the rights of and responsibility for unidentified students with disabilities.** Proposals would exonerate local education agencies from accountability for unidentified students unless the parents express concern in writing. This would effectively remove the current requirement that schools identify, locate and evaluate children with disabilities. The burden to assure an appropriate education for many students would be shifted to parents who may not even be aware of the I.D.E.A. Data reported by the U.S. Department of Education indicate many students with serious emotional disturbance go unidentified as needing special education supports.

How will progress towards the educational inclusion of children with disabilties be affected by the changes being proposed to Part B?

To guard against the arbitrary segregation of children with disabilities, the authors of **Part B** of the I.D.E.A. developed specific safeguards in the law. These are processes that schools must go through before they can remove children with disabilities from their home schools and classes. The I.D.E.A. placed the burden of proof on the schools to demonstrate that children with disabilities cannot be educated in the least restrictive environment with the provision of supports and aids. Under the current **Part B,** schools cannot arbitrarily move a child if parents don't agree. Moreover, the I.D.E.A. has required and resulted in best practices, research and other information to assist schools in educating children with disabilities with their peers without disabilities. Since 1975, it has, as intended, enhanced the capabilities of the schools to educate children with and without disabilities together.

As a result of the safeguards **and** the development of best practices, excellent progress has been made to support children with and without disabilities being educated together. Case law has also confirmed and supports the schools' responsibilities to provide appropriate supports and services to assure children with disabilities succeed in regular schools and classes. Additionally, over the last decade, a growing coalition of adults with disabilities and parents have advanced the benefits of inclusion for both children with and without disabilities. As a result of all of the above, the movement toward inclusion has gained momentum and strength. This progress towards inclusion is a strong motivator for the **NEA, AFT, NASB, NASSP, NAESP AND AASA.** The changes being pursued by the above groups will allow them to remove children without being in conflict with federal law and effectively end the positive progress towards inclusion.

Why shouldn't students with disabilities be subject to disciplinary procedures? Aren't they totally exempt from discipline under the current I.D.E.A.?

Everyone is concerned about dangerous behaviors in our public schools. It is reasonable to expect that students receiving special education may reflect the same trends as their peers who are not disabled. However, there is absolutely no evidence to support that students with disabilities have an especially high incidence of dangerous behavior. The information being

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promoted by the education groups asserting that growing numbers of students with disabilities in America's schools is causing the rise in violence is simply unfounded. They are using their positions of influence to place all of the problems of education on the backs of children with disabilities.

The I.D.E.A. does not prevent students with disabilities from being disciplined for violent or dangerous behavior. In fact, a good I.E.P. will assure that the problem behaviors change to the student's and the school's advantage. Students who violate school discipline codes also may be subject to the same consequences as other students, including suspensions of up to ten school days. However, if a school wants to change a student's placement for discipline reasons (move to a more restrictive placement or exclude from school for more that ten school days), the law requires the school to follow due process procedures found in Part B of the I.D.E.A. These procedures are to protect against a repeat of history when students with disabilities were arbitrarily placed in highly restrictive segregated settings or totally excluded by administrators who didn't want to be responsible for their education.

Aren't more and more children in special education causing a burden to the schools? Is it fair to the majority of students to spend so much money on special services?

Educating all children effectively is expensive. For students with disabilities who require special education, the cost of their services, supports and accommodations ensures that they can benefit from school. The large figures quoted by school administrators and reported in the media are largely anecdotal and misleading. For example, the I.D.E.A. does not require school administrators to send students to costly private schools such as recently reported in the television media. The only reason schools can be compelled to send students to private schools is evidence that they are not providing an appropriate education for the student. Schools who report large numbers of students in private placements and then complain about them are reporting inadequacies in their own schools. What has gone unsaid in media accounts is how many schools have **chosen** not to provide an education for these children in their own schools and districts.

It is important to note that special education dollars aren't taken away from general education. Federal and state special education dollars supplement regular education dollars for the additional costs of educating students with disabilities.

Isn't litigation brought by parents of students with disabilities costing schools and one of the reasons special education is so costly?

No. Less than 1 percent of all families of children receiving services under the I.D.E.A. nationwide have ever filed due process claims against their local schools. Of those cases, public schools are liable for attorneys' fees and associated costs only when parents prevail. This successfully guards against frivolous claims. Families generally do not take filing complaints lightly. Due process procedures can be long and grueling and can take tremendous emotional and financial tolls on the entire family. The assertion by education groups that due process is some kind of a gravy train for parents is ridiculous. By "gutting" Part B of the I.D.E.A., Congress would successfully remove all recourse for children with disabilities and their parents in seeking their educational rights.

The proposed legislation that eliminates the Part B procedural safeguards for children with disabilities and their families also contained some language that was meant to improve Part B. Shouldn't I support those good changes?

Part B of the I.D.E.A. **currently** provides the basis to assure good educational outcomes for students with disabilities. The changes being proposed in Congress would eliminate many critical underlying principles. In the long run, any positive changes that may come out of negotiations would be outweighed by the elimination of basic educational rights. The unnecessary opening of Part B puts parents and advocates in the unfavorable position of negotiating the rights of children with an unfriendly Congress being persuaded by powerful education groups. In fact, during the 104th Congress, parents and advocates were held hostage to the negotiation process. The rights of children should never be negotiated and the authors of Part B permanently authorized it to guard against this kind of attack against children with disabilities.

It is true that some "good changes" are being proposed in the same legislation that will harm the basic rights of children with disabilities. In particular, the United States Department of Education wants additional requirements for the I.E.P. and to remove the States' abilities to provide schools with funding incentives for highly restrictive segregated settings. These "improvements" can be accomplished through the full implementation and enforcement of the current Part B. The Center for Law and Education has written a policy paper commenting on the United States Department of Education's proposals to amend Part B. The paper makes a compelling case that **Part B has never been fully implemented and enforced and already provides a legal basis to accomplish what the Department wants to accomplish.** The paper is available through requests to **A GOOD I.D.E.A.** (410-828-8274) or by contacting any of the groups and individuals named on the endorsement list at the end of this document.

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What can I do?

- Contact the people on the attached "Key Players - I.D.E.A." list to communicate the **A Good I.D.E.A.** message. Also, be sure to contact members of the Congressional Committees from your own state.

- Organize a grass roots campaign in your State. You may request someone to meet with your group to provide information regarding this issue and/or assistance in organizing a grassroots effort to save Part B of the I.D.E.A.

- Call, write, e-mail or fax for information on a post card campaign and how you and your group can get involved.

- Add your organization's name to the following list supporting the position by completing and sending the information.

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A Good I.D.E.A.

Keep the Rights, Realize the Promise

PART B ALREADY:

Protects Kids
Protects Schools
Protects Families

Don't Change It!! Make It Work!!

1) Don't change Part B of the Individuals with Disabilities Education Act (I.D.E.A.). It is permanently authorized.

2) Permanently authorize early childhood education for children from birth through age 3 (Part H).

3) Reauthorize the discretionary programs that were intended to make Part B effective.

4) Help I.D.E.A. meet the promise. Increase appropriations for IDEA.

Affiliation: ______________________ List affiliation only? ______________________

Name: ______________________ List name first? ______________________

Address: ____

____

Phone: ______________________ Fax: ______________________

Email: ______________________ Congressional District: ______________________

PLEASE FAX BACK TO: TASH (410) 828-6706
QUESTIONS? Call Marcie Roth @ (410) 828-8274 X104

ENDORSEMENT LIST AS OF JANUARY 30, 1997:

TASH US

National Down Syndrome Congress

Schools Are For Everyone (SAFE)

The Grassroots Consortium on Disabilities

The Center for Law And Education

Family T.I.E.S. Network (IL)

PEAK Parent Center (CO)

National Association of Protection and Advocacy Systems (NAPAS)

Endependence Center (VA)

The Autism National Committee

Self Advocates Becoming Empowered

PACER Center (MN)

Illinois Planning Council on Developmental Disabilities

Federation for Children with Special Needs (MA)

Public Interest Law Center of Philadelphia (PILCOP)

Ohio Coalition for the Education of Children with Disabilities (OCECD)

Michigan Citizens Alliance to Uphold Special Education (CAUSE)

Institute on Community Integration-University of MN

Rammler & Wood Consultants (CT)

ABC Coalition (MD)

Sinergia, Inc. (NY)

Autism Support & Advocacy in PA

Parents Union for Public Schools in Philadelphia (PA)

Pennsylvania Developmental Disabilities Council

Barbara & M. Wayne Dyer (TN)

Fredda Brown and Elizabeth Erwin -City U. of NY

Laurie Draves (TN)

Beverly Rainforth- State University of New York

Parent Information Center (NH)

Ian Pumpian- San Diego State University (CA)

Parent Education Network (PA)

Mental Health Association in Butler County (PA)

Partners Resource Network (TX)

Exceptional Children's Assistance Center (NC)

Virginia TASH

Michigan Association of School Social Workers

New Jersey TASH

Coalition of Citizens with Disabilities in Illinois

Arizona TASH

United Parent Support for Down Syndrome (IL)

Louisiana TASH

Southern Illinois Center for Independent Living

Florida TASH

IMPACT, Inc (IL)

California TASH

Family Support Network (IL)

Illinois Migrant Head Start Project

David C. Shaw, Attorney at Law (CT)

SAFE - Connecticut

Connecticut Coalition for Inclusive Education

Parents Place of MD

Southwestern Connecticut Coalition for Inclusive Education

Vermont Parent Information Center

Advocates Network (IL)

Fox River Valley Center for Independent Living (IL)

Northwestern Illinois Center for Independent Living

Central Illinois Center for Independent Living

Advocates United (IL)

Creating Opportunities for Parent Empowerment (DC)

Kentucky Parent Information Center

Nebraska Parents Center

Educating Minority Parents: Opening Windows to Educational Rights (MS)

Family Resource Center on Disabilities (IL)

Parent Partners (MS)

National Center for Latinos with Disabilities (IL)

Iowa Pilot Parents

Over 90% of the Parent Training and Information Centers have also endorsed this position.

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A GOOD I.D.E.A. !!!

KEY PLAYERS — I.D.E.A.

Send the IDEA Message by Mail, Fax or E-mail To the Following Individuals:

President Clinton
1600 Pennsylvania Ave. NW
Washington, DC 20500
FAX: (202) 456-2461

Representative Frank Riggs
1714 Longworth House Office Building
Washington, DC 20515
FAX: (202) 225-3403
Phone: (202) 225-8811

Senator Jim Jeffords
513 Senate Hart Office Building
Washington, DC 20515
E-mail: Vermont@jeffords.senate.gov
FAX: (202) 228-0338
Phone: (202) 224-5141

Senator Trent Lott
SR-487
Washington, D.C. 20515
FAX: (202) 224-2262

Senator Tom Harkin
SH-531
Washington, D.C. 20515
E-mail: tom_harkin@harkin.senate.gov
FAX: (202) 224-9369
Phone: (202) 224-3254

Dr. Patricia Morrissey
Senate Labor/HHS/Education
SD-428
Washington, D.C. 20515
FAX: (202) 224-5044
Phone: (202) 224-5375

Secretary Richard Riley
Department of Education
600 Independence Ave. SW
Washington, DC 20202
FAX: (202) 401-0596

Representative Bill Goodling
2263 Rayburn House Office Building
Washington, DC 20515
FAX: (202) 226-1000
Phone: (202) 225-5836

Representative Newt Gingrich
U.S. Capitol, Room 232
Washington, D.C. 20515
E-mail: georgia6@hr.house.gov
FAX: (202) 225-4656

Senator Ted Kennedy
SR-315
Washington, D.C. 20515
E-mail: senator@kennedy.senate.gov
FAX: (202) 224-2417
Phone: (202) 224-4543

Mr. Bruce Reed
White House
1600 Pennsylvania Ave. NW
Washington, D.C. 20500
FAX: (202) 456-2461

Ms. Sally Lovejoy
House Committee on Education
and the Workforce
2181 Rayburn
Washington, D.C. 20515
FAX: (202) 225-9571
Phone: (202) 225-4527

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1-800-962-3524

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Participation in Content-Area Classes and Community-Based Instruction in Secondary Schools:

Isn't It About Achieving a Balance?

BY JOHN MCDONNELL, PH.D., UNIVERSITY OF UTAH

The author would like to thank Andrea McDonnell, Rob O'Neill, and Dick Kiefer O'Donnell for their recommendations on earlier drafts of this paper.

Correspondence regarding this paper, as well as requests for a full set of references, can be sent to John McDonnell, Department Chair, Department of Special Education, MBH 221, University of Utah, Salt Lake City, Utah, 84112.

I [am responding] to Carol Tashie and her colleagues' article on high school inclusion which appeared in the September 1996 issue of the TASH *Newsletter*.

Tashie, Jorgensen, Shapiro-Barnard, Martin, and Schuh (1996, September) present a powerful argument for the participation of students with severe disabilities in content-area classes at the secondary level. Their article had a number of important insights and recommendations for both practitioners and researchers. I applaud their continuing efforts to grapple with this knotty problem and develop practical strategies for supporting students in these settings. Although I strongly support the practice of including high school students with severe disabilities in content-area classes, I take issue with Tashie and her colleagues' critique of community-based instruction and its role in meeting the educational needs of this group of students.

My concerns center around three points.

- First, their definition of "full inclusion" is inconsistent with the structure and organization of most high schools.
- Second, they do not adequately address the call by researchers in both general and special education to "anchor" classroom instruction to real life contexts and settings.
- Finally, they ignore the limitations of our current technology in providing effective and efficient instruction for students in content-area classes. From my perspective, these issues do not argue against the participation of students in content-area classes but instead for careful consideration by the student's IEP team in determining which instructional approaches will best meet the student's needs.

Inclusion and High Schools

Tashie and her colleagues define inclusion as the participation of students in content-area classes for the entire school day. Thus, they reject community-based instruction as an exclusionary practice that will have a negative impact on the participation of students in the natural social networks of the school. Their position is based on the belief that students must have equal access to the same opportunities as their peers without disabilities.

While I agree wholeheartedly that the principle of equal access is fundamental to successful inclusion, I am somewhat disconcerted by their implication that "equal access" can only mean one type of educational experience. Their position ignores the incredible diversity of alternative educational experiences available to students without disabilities in most comprehensive high schools today. Anyone who has spent much time in high schools realizes that it is quite common for students without disabilities to leave the school building for a variety of educational purposes. Sometimes these off-campus experiences are done as part of a content-area class, but frequently they are done individually and are tailored to meet the unique needs of students. These experiences can include service learning classes, vocational or career training, or attending classes at a local university, college, or community college for credit. As such, the contention of Tashie and her colleagues that community-based instruction for students with severe disabilities is inconsistent with the educational experiences of students without disabilities is not valid.

A more important question, of course, is whether such off-campus experiences are detrimental to the successful "inclusion" of the student in the school. Tashie and her colleagues argue that going off-campus to receive instruction reduces the amount of time that a student is in contact with peers at school and thus, may affect the student's potential involvement in the social networks of the school. However, there is no empirical evidence that suggests that community-based instruction negatively affects the acceptance of students by their peers without disabilities or impedes the development of friendships or other relationships in school. In addition, an alternate argument can be made that off-campus instruction does not reduce a student's inclusion but expands it beyond the social networks found at school. Whether these social networks are as important to the student as those that he or she is involved in at school is matter of personal preference.

In reality, inclusion means different things to different people. From that standpoint, it seems unlikely that we can arrive at a consensus about what inclusion means for *all* students. Further, while "equal access" is an important principle underlying the inclusion movement, so is accepting the differences of each student. As Martha Minnow (1990) points out in her book Making All the Difference: Inclusion, Exclusion, and American Law, "If equality depends on "sameness," then the recurrence of difference undermines chances for equality" (p. 74). The perception of Tashie and her colleagues that community-based instruction is exclusionary does not stem from the fact that students leave school to learn but from their own unique definition about what it means to be included.

In my view, the decision about whether the student should participate in content-area classes, community-based instruction, or a combination of these approaches should be made by the student and the people that are the most involved in their life. As Giangreco & Putnam (1991) point out in their discus-

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sion about the potential conflicts between a student's participation in content-area classes and community-based instruction in secondary schools:

> . . . at some level, the question might not be unlike that personal balance that each of us strives to attain between "work" and "play" in our lives: How can we strike a similar balance for a child with severe disabilities? (p. 263)

Let's Get Real: Anchoring Instruction to Actual Performance Contexts

During the last decade, leading educators and psychologists have raised serious questions about the "transfer assumption" underlying the traditional model of education for students without disabilities (Berryman, 1993; Bodilly et al, 1993; Brown, Collins, & Duguid. 1989; Lave, 1991; Resnick, 1987; Statz et al, 1993; Stern, Raby, & Dayton, 1993). For example, Berryman (1993) states " . . . research, extensive and spanning decades, shows that individuals do not *predictably* transfer knowledge in any of the three situations where transfer should occur. They do not predictably transfer school knowledge to everyday practice . . . They do not predictably transfer sound everyday practice to school endeavors . . . They do not predictably transfer their learning across school subjects." (pp. 371-372, italics in the original). A common explanation for this situation is that much of the learning that goes on in schools is decontextualized from actual performance contexts (Berryman. 1993; Resnick, 1987). That is, there are no conceptual, functional, or instructional links between the skills that students learn in school and to the tasks and settings in which they must apply them.

The inability to "transfer" or generalize knowledge learned in school to actual performance settings is not unique to students without disabilities. There is a significant research base documenting that students with severe disabilities do not readily generalize skills learned in one environment to another (Albin & Horner, 1988; Hughes. 1994; Horner, McDonnell, & Bellamy, 1986; Stokes & Baer, 1977). In fact, most research suggests that students with severe disabilities will require direct instruction in actual settings to assure successful performance (c.f., Albin & Horner, 1988; Hughes, 1996; McDonnell, Mathot-Buckner, & Ferguson 1996).

It seems to me that the problem isn't really whether students with severe disabilities receive community-based instruction but that many students without disabilities do not. As such, Tashie and her colleagues miss the point when they suggest that students should not receive community-based instruction because some students without disabilities are not provided with similar opportunities. All students, including those with severe disabilities, will experience more success in school when teachers begin to design a curriculum that is anchored to real life contexts and when instruction incorporates community-based learning activities. Although achieving this is a much more difficult task than simply not providing community-based instruction to students with severe disabilities, it is the only approach that has any real potential for ensuring that all students receive an effective education.

In the interim, I believe that the only reasonable approach for professionals is to provide community-based instruction when IEP teams decide that it is the best for the student and to get actively involved in reform efforts in their school. At the systemic level, special educators need to expand their focus from simply providing quality education for students with disabilities to providing quality education for *all* students.

Limits In Our Technology: Doing the Best with What We Have

While research clearly shows that the participation of students with severe disabilities in content-area classes produces significant social benefits for students, its effect on educational achievement is still unclear (Giangreco & Putnam, 1991; McDonnell, under review). I agree with Tashie and her colleagues that the general education curriculum and content-area classes can provide students with a rich array of educational experiences. I also firmly believe that many students with severe disabilities can master a number of the concepts and operations presented in these classes. Unfortunately, I know of no empirical studies that demonstrate that this occurs consistently across all students or subject areas. In addition, while there is some evidence that the rate of interaction students have with peers without disabilities is predictive of the number of IEP goals that they achieve (c.f., Brinker & Thorpe, 1984) and that instruction in typical classes can be modified to allow student's to master critical routines, activities, and skills (c.f., Hunt, Staub, Alwell, & Goetz. 1994), we are far from having a well defined instructional technology for assuring that student learning will occur consistently and in an efficient manner in all content-area classes.

As Fantuzzo and Atkins (1992) have noted there is a pressing need for special educators and applied behavior analysts to ". . . develop more adaptive and effective strategies to promote academic and social competency, and develop strategies that teachers and school personnel *can* and will actually use." (p. 37; italics in original). Most of what we have learned about how to teach was developed to 'fit" within a service delivery model that separated students from their peers in self-contained programs. We do not know if we can modify these instructional strategies to the match the complexity of general education classrooms, and if we can, whether they will have the same effects on student learning (McDonnell, under review).

While some advocates emphatically state that schooling is ": . . . about friendships . . . ", I believe that it is also about students learning the broad array of routines, activities, and skills that will empower them to improve the immediate and future quality of their lives. Given the current limitations in our teaching technology, it seems to me that a more cautious and thoughtful approach to the wholesale participation of secondary students with severe disabilities in content-area classes is appropriate. We need to critically evaluate whether *all* of a student's educational needs can be met in these settings. I suspect that if we do this with an open mind that we will conclude that sometimes they cannot and that strategies like community-based instruc-

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Selected Resources and Reports on Community Integration

The Center on Human Policy, through its National Resource Center on Community Integration and its subcontracts with the University of Minnesota's Research and Training Center on Community Living and Responsive Systems Associates, distributes a variety of reports and resources on the integration of people with severe disabilities into community life. The project would like to make these reports available to you at cost. Due to space limitations this is a partial listing; a complete list is available upon request.

INFORMATION PACKAGES

NEW!

Innovative Practices in Supported Living: An Overview of Organizations, Issues, and Resource Materials (1996) edited by Kathy Hulgin, with Bonnie Shoultz, Pam Walker and Steve Drake, is a comprehensive resource package on supported living. It includes examples of agencies around the country that are successfully implementing a supported living approach and a discussion of related issues, such as housing and person centered planning. It also includes an annotated bibliography of written materials and information about World Wide Web sites that address supported living issues. (66 pages) $3.95

Selected Issues in Family Support: A Compilation of Materials and Resources (1995) by Pam Walker focuses on selected issues in family support, including: family support principles; limitations of family support programs (related to race/ethnicity, culture, poverty, women, etc.); permanency planning; and state-level systems change advocacy. It contains various articles and annotated references relevant to these issues. (37 pages). $3.00

Multiculturalism and Disability: A Collection of Resources (1993) by Susan O'Connor includes an overview article which offers a discussion on how disability should be included in the multicultural dialogue and an annotated bibliography of readings, organizations and resources dealing with multicultural issues. (70 pages) $4.20

Personal Relationships and Social Networks: Facilitating the Participation of Individuals with Disabilities (1991) by Zana Marie Lutfiyya includes an overview article, three articles which describe the experiences of people with disabilities who have nondisabled friends and are part of a network of people, and an annotated bibliography. (99 pages) $5.15

Materials on Self-Determination (1990) by Bonnie Shoultz, Michael J. Kennedy and Nirmala Erevelles includes an overview article on self-advocacy and an annotated bibliography. (12 pages) $2.00

SITE VISIT REPORTS

NEW!

Jay Nolan Community Services: The Advantages and Dilemmas of Converting Quickly from Group Homes to Supported Living Services (1996) by Kathleen Hulgin describes the strategies and challenges of changing from group homes to supported living in an agency serving people with autism and other developmental disabilities. (22 pages) $2.65

Job Path: Shifting the Focus Beyond Just Work (1996) by Kathleen Hulgin and Julia A. Searl describes how an organization in New York City began to develop alternative day services for people with severe disabilities. (22 pages) $2.70

From a Community Residence to a Home of Their Own (1995) by Pam Walker describes how the Syracuse Developmental Services Office, in Syracuse, New York, facilitated the process of home ownership for two women previously living in a community residence.
(15 pages) $2.40

"Like an Angel that Came to Help Us": The Origins and Workings of New Hampshire's Family Support Network (1993) by Bonnie Shoultz is a description of New Hampshire's innovative family support services. It details the legislative history of the program as well as its implementation throughout the state, and draws lessons for others interested in developing family-centered programs. (52 pages) $3.70

RESOURCE MATERIALS

UPDATED!! **Community Integration Policy and Practice Abstracts** (1996) prepared by Julia Searl is an updated compilation of recent journal articles relevant to community integration for people with developmental disabilities and includes topics of education, employ-

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ment, policy, communication and supported living. (29 pages) $3.85

Serving Children with Special Needs in Your Child Care Facility (1996) edited by Julia Searl is a manual that gives information to child care providers on including children with disabilities in their facility. It includes the steps of setting up a collaborative inclusive program for preschoolers, and has numerous resources that may help the process, such as how to help staff work as a team. (46 pages) $4.95

A Checklist for Evaluating Personal Assistance Services (1993) by Connie Lyle O'Brien and John O'Brien provides a way of evaluating the effectiveness of policies and/or programs providing personal assistance services by looking at dimensions such as availability, comprehensiveness and participant control. (10 pages) $2.00

Making a Move: Advice From People First Members About Helping People Move Out of Institutions and Nursing Homes (1990) by Connie Lyle O'Brien and John O'Brien shares the perspective of about 40 People First members on how People First members can help people moving from institutions and nursing homes. (7 pages) $1.80

Against Pain as a Tool in Professional Work on People with Severe Disabilities (1989) by John O'Brien is an essay arguing against the use of pain, often cloaked in the terms "aversive treatment" and "intrusive procedures" for the control of people with severe disabilities. (12 pages) $1.95

NEWSBULLETINS

Feature Issue on Supporting Diversity (Summer 1996) edited by Betty Horton, Marijo McBride and Bonnie Shoultz explores ways in which services are and could be supporting people from diverse groups. It also highlights a number of individuals who tell their own stories. This bulletin was published through the Impact series of the Institute on Community Integration at the University of Minnesota in cooperation with the Center on Human Policy. Single copies free if requested. For 2 copies or more, please contact:

Institute on Community Integration
University of Minnesota
109 Pattee Hall, 150 Pillsbury Drive, S.E.
Minneapolis, MN 55455
(612) 624-4512 FAX (612) 624-9344

Feature Issue on Institution Closures (Winter 1995/96) edited by Mary F. Hayden, K. Charlie Lakin, and Steve Taylor contains national information as well as a variety of articles on closing institutions written from the perspectives of self-advocates, professionals, parents, researchers, and policy makers. This bulletin was published through the Impact series of the Institute on Community Integration at the University of Minnesota cooperation with the Center on Human Policy. Single copies free if requested. For 2 copies or more, please contact:

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Policy Bulletin on Safeguards (1993) addresses how safety can be increased by strengthening community and improving the assistance people receive. It also discusses the paradox of regulations. (18 pages)

Policy Bulletin on Disability and Family Policy (1992) presents a multicultural approach for working with families, focusing on class, gender, and cultural dimensions, with recommendations for policy makers. (10 pages)

Policy Bulletin on Social Relationships (1991) is first of a series of bulletins summarizing research findings for those who make and are impacted by policy. This 8-page document looks at relationships between people with and without disabilities. (8 pages)

Community Living for Adults (1989) is a newsbulletin highlighting promising practices, issues and resources in supporting adults in the community. (16 pages)

Families for All Children (1987) highlights promising practices in family support services nationally, the Center on Human Policy's statement in support of families and their children, and issues and resources in family support. (12 pages)

Single copies of all newsbulletins are free if requested with your order. Newsbulletins are $.75 per copy for bulk orders of 2-10 copies; $.50 per copy for bulk orders of 10 and up.

PAPERS AND ARTICLES

Disability Studies and Mental Retardation (1996) by Steve Taylor is a reprint (Disability Studies Quarterly, 16(3), 4-13) that applies a disability studies perspective to the study of people labelled as having mental retardation or cognitive disabilities and examines mental retardation as a social and cultural phenomenon. The article includes an extensive annotated bibliography on mental retardation and disability studies by Steve Taylor and Perri Harris. (10 pages) $2.50

The Disability Blanket (1994) by Michael J. Kennedy is a reprint of an article (Mental Retardation, 32(1), 74-76) that represents the experience of how it feels to be under a one-size-and-fabric-fits-all blanket, and offers a vision for change. (3 pages) $1.60

Down Stairs that are Never Your Own: Supporting People with Developmental Disabilities in Their Own Homes (1994) by John O'Brien is a reprint of an article (Mental Retardation, 32(1), 1-6) that discusses the historical and current meanings and dimensions of "house" and "home" for people with developmental disabilities. (6 pages) $1.80

Assistance with Integrity: The Search for Accountability and the Lives of People with Developmental Disabilities

continued on page 27

(1993) by John O'Brien and Connie Lyle O'Brien is a discussion piece, intended to stimulate controversy and dispute, about support for people who rely on service providers for 24-hour assistance. It addresses the field's concerns about such issues as safety, quality, and the potential for abuse, and calls for major reorganization of the current system of service provision. (50 pages) $3.35

Finding a Way to Everyday Lives: The Contribution of Person Centered Planning (1993) by John O'Brien and Herbert Lovett represents the insights that emerged from a Pennsylvania gathering of people experienced in various approaches to person-centered planning and administrators interested in learning more about it. (19 pages) $2.35

Unlikely Alliances: Friendships and People with Developmental Disabilities (1993) by John O'Brien and Connie Lyle O'Brien is a reflection on the nature of friendship, on four of its dimensions, and on the meanings of friendship for people with and without developmental disabilities and the communities they inhabit and create together. (33 pages) $2.80

A Child's Birthright: To Live in a Family (1990) edited by Nancy Rosenau leads the reader through a vicarious tour of Macomb-Oakland Regional Center's approach to and services for children with developmental disabilities and their families, with an emphasis on permanency for every child. (51 pages) $3.50

Relationships with Severely Disabled People: The Social Construction of Humanness (1989) by Robert Bogdan and Steven J. Taylor is a reprint of an article (Social Problems, 36(2), 135-148) that presents the perspectives of nondisabled people who do not stigmatize, stereotype, and reject those with obvious disabilities. (14 pages) $2.05

On Accepting Relationships Between People with Mental Retardation and Nondisabled People: Towards an Understanding of Acceptance (1989) by Steven J. Taylor and Robert Bogdan is a reprint of an article (Disability, Handicap & Society, 4(1), 21-26) that outlines the sociology of acceptance, a theoretical framework for understanding relationships between people with mental retardation and typical people. (16 pages) $3.05

Permanency Planning for Children and Youth: Out-of-Home Placement Decisions (Exceptional Children, 55(6), 541-549, copyright 1989 by the Council for Exceptional Children) by Steven J. Taylor and K. Charlie Lakin advocates the extension of the basic protections of "permanency planning" to all children and youth, including those with severe handicaps. Reprinted with permission. (9 pages) $1.85

The Kid From Cabin 17 (1988) by Pamela Walker and Betsy Edinger is a reprint of an article (Camping Magazine, May, 1988, 18-21) which tells the story of Chauncey's summer camp experience and the lessons learned about the integration of children with severe disabilities. (4 pages) $1.60

EVALUATIONS AND ADVOCACY REPORTS

NEW!

Evaluation of the Self-Directed Personal Services Program Operated Through Enable (1996) by Pam Walker, Steve Taylor, Julia Searl, Bonnie Shoultz, Kathy Hulgin, Perri Harris, and Mary Handley is an evaluation report of the Self-Directed Personal Services program run by Enable, in Syracuse, New York. The program, which includes people with a wide range of disabilities, includes some aspects of consumer control. At the same time, systemic constraints to control are discussed. (24 pages) $2.70

Permanency Planning in Michigan: From Philosophy to Reality (1994) by Bonnie Shoultz, Susan O'Connor, Kathy Hulgin, and Paul Newman is a study and policy analysis of Michigan's permanency planning efforts, including successes and challenges, for children with developmental disabilities and mental health needs. The report is based on interviews with parents, state and local staff members, and administrators. (67 pages) $4.35

Negotiation: A Tool for Change (1979) by Steven Taylor describes basic negotiation strategies and how they can be used to work for change. The paper outlines specific strategies for effective negotiation, including preparing for and following up on negotiation sessions. (10 pages) $2.25

Principles of Whistleblowing (1979) by Douglas Biklen and Milton Baker contains a list of suggestions for "whistleblowers," staff and others who want to call public attention to rights violations at service agencies. (5 pages) $2.10

* * *

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* * *

The preparation of this listing was supported in part by the National Resource Center on Community Integration, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133D50037. No endorsement by the U.S. Department of Education should be inferred. The Center on Human Policy subcontracts with TASH for space in this newsletter.

One Parent's Perspective

BY LISA BAACH

Lisa Baach is active in local education issues in Maryland. She represents Schools Are For Everyone, Inc. in Washington, D.C.

Grassroots

During discussions on proposed changes to the IDEA, advocates inside the Beltway always lament the lack of a vocal grassroots. But given my experience with the federal level of special education, I'm always amazed that the grassroots does as much as it does.

I had my first encounter with the "feds" about ten years ago. I decided to appear before an Office of Special Education and Rehabilitative Services (OSERS) monitoring team and I persuaded my friend, Kathy, to drive an hour and a half out to Hagerstown, Maryland, to give testimony. Kathy and I shared the experience of having had premature twins and we shared an impassioned belief that our preschool twins should be able to attend school together, regardless of disability. Since that was a totally foreign notion in our district, we were going to give the feds an earful about what was going on.

We ultimately realized that our testimony hadn't made a single bit of difference. Of course, the feds found least restrictive environment (LRE) violations; they could hardly be missed. But little in our district has changed as a result.

Every time I hear someone from inside the Beltway talk about how we have to get the grassroots to lobby for such and such, I think about Kathy. I ask myself this question: can I say to Kathy in good conscience that this issue has a real impact on kids with disabilities, that her voice is important, and this is the way she should use her voice? Sometimes the answer is definitely yes, but sometimes it would be like asking her to drive to Hagerstown.

Disruptive Students

Of course, most of the discussion around IDEA involves the discipline of disruptive students. The school administrators, the teachers' unions, they're all tired of having to deal with disruptive students. Well, I'm tired, too. I'm tired of getting notes telling me that my son has had another bad day in school. What is the point of that kind of communication? What am I supposed to do with the information, send him to bed without dinner? What caused the disruption and what is the school going to do about it? I doubt that you could find any expert in the field of parent/school relationships who would argue that it is a good thing for teachers to write hostile and negative notes to parents just so they can "let off steam." So why is it permitted? I think this should be part of the "debate" around the issue of disruption.

> ***I didn't grow up in the Nation's Capital but when I finished law school, it seemed like a great place to work for a few years. Now, twenty years later, I am here with a husband, three kids, and a dog. I think it may be time to admit that I am, in fact, from inside the Beltway. From this viewpoint, let me describe how I see the talk about changing IDEA***

Attorney's Fees

As the parent of a child with challenging behavior, I have been told over and over again that, "If negative behavior is not "consequenced," it will be repeated. If that is the belief, shouldn't it also be true for systems as well as children? What about my son's school, the school district, the whole state, the whole country? What have been the negative consequences for the massive failure to implement the law?

There is a federal judge in Baltimore, Maryland, who - in a 45-page decision - "consequenced" our school district for its persistent failure and refusal to provide extended school year (ESY) to students with disabilities. The judge required the district to reimburse the Maryland Disability Law Center for years of work they put into the case. Sure enough, just as the research suggests, the district now behaves differently when it comes to ESY.

Perhaps some day we will be able to add to our repertoire of behavior modification, such as extended time-outs for school administrators, and teachers who fail to comply with federal law. Or tangible rewards for teachers who demonstrate positive behaviors. In the meantime, it is very important to keep the few current avenues of consequencing open by preserving access to federal court and the recovery of attorney's fees.

Changes to the IEP

The failure to enforce the current law has dimmed my enthusiasm for many of the "good" changes to IDEA that are currently under consideration. Policy leaders have developed some proposed "refinements" or "clarifications" intended to improve special education. For instance, there is a proposal which would require local education agencies to include a "justification" for a student's removal from regular education with non-disabled peers; the current law only requires a "statement" as to the reasons for such removal. Now, I can see why the word "justification" is better than the word "statement". But where I live, for years the system didn't even bother to include statements in the IEPs of students who were in totally segregated facilities. With the help of the Maryland Coalition for Inclusive Education I filed a complaint with the Office of Civil Rights and, sure enough, after months and months of investigation, a finding was made that the school system had indeed violated the civil rights of students. For sure, they are going to include those statements now.

Not all kids have left the centers as a result of the complaint. In truth, the students in the segregated facilities are there because the parents feel that their children will be teased or even physically abused in a diverse setting. That, of course, should never happen but it does. My question is, is there a word in IDEA

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One Parent's Perspective

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we could change that would eliminate such bigotry and cruelty ? If so, I'd fight like hell for it. But to change "statements" to "justifications"?

There is another proposed change which is supported by some very good folks, but has caused great anxiety among some other equally good folks. The bill introduced by the administration last year would have eliminated the need for schools to identify "short term objectives" in a student's IEP. Instead, the schools would be required to include a statement of annual objectives.

Some advocates are concerned about what might happen if we eliminate "short term objectives." I agree that "short term objectives" can be very valuable. Alec alone has had about 9,000 of them and I'm sure he has achieved many of them. Personally, I would give all 9,000 for a single phone call from one of Alec's classmates. In fact, if there are to be revisions to Part B of IDEA maybe this could be one: give parents a choice between short term objectives on the IEP or one phone call from one classmate per grading period. I think it would be a fair measure of parents' relative interest in both issues.

In the End

Once in awhile I will go to a meeting and sit in a conference room in some building in downtown D.C., listening to really well-meaning policy analysts and lobbyists from national advocacy organizations. They debate the subtle nuances of these clarifications and refinements and strategize about how to interest millions of local parents in these issues. I think to myself, "Wouldn't it be nice if this talent and commitment and energy was dispersed throughout classrooms instead of in this conference room ?"

**Once again,
our sincere thanks to
Joyce and Don Buell
and their family for their
extremely generous
contribution!**

Community-Based Instruction

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tion will be the best way to help a student meet their goals.

Summary

I believe that "full inclusion ' is an achievable goal for people with severe disabilities. But I also believe that the definition of full inclusion is uniquely personal and varies significantly from one person to another. If we are going to be responsive to these differences, it will mean that IEP teams must carefully assess when a student's educational needs are best met in content area classes and when they are best met through community-based instruction. There is no doubt that we need to continue to push the envelope and challenge our assumptions about what is possible. In this sense, Tashie and her colleagues make an important contribution in shaping the future of education for students with severe disabilities and our field. But as we move toward inclusive education programs for all children we need to remember that it's not just about ' equal access" but also about acceptance of diversity and choice. I believe that our ongoing dialogue about inclusion needs to focus on how to create educational environments that can accommodate the educational goals and needs of all children, not on making everyone's educational experiences the same. We must weigh all of the possible strategies that can be used to meet a student's needs and find ways to balance them so that both the educational and social outcomes of schooling are achieved.

RESPONSE:

We (Tashie, Jorgensen, Shapiro-Barnard, Martin, and Schuh) thank McDonnell for his thoughtful response to our *current* articles, publications, and workshops on full inclusion for secondary students with severe disabilities (Tashie & Schuh, 1994, Tashie, et al. 1996, Shapiro Barnard, et al,, 1996, Jorgensen & Tashie, 1996). McDonnell expresses several points of agreement, as well as several points of dissension with our work. This discussion serves to further the field's understanding of a critical issue in education today. We appreciate the forum.

TASH has offered to continue this dialogue, and invite others to contribute to this ongoing conversation. There are many areas in which we and McDonnell wholeheartedly agree, particularly in the need to become actively involved in general educational reform. Our efforts must continue to emphasize the ways schools can be restructured so that "the inclusion of each student in the mainstream of regular education is a necessary condition for achievement of excellence by all." (Jorgensen, 1993). With such restructuring, there might no longer be a need to grapple with issues of separate classes, separate community experiences, or different standards for students with disabilities. Students with disabilities would be viewed, not as special education students, but as valued members of the student body.

However, we do take issue with several of McDonnell's assertions, primarily with respect to the definition of inclusion. In our opinion, inclusive education is defined as supporting all students to be fully involved *in what is typical and valued in their particular schools*. Education -- and thus inclusion -- in a high school where all students are involved in classroom and community-based learning looks dramatically different than in a school that adheres to a schoolbased model of education. High school inclusion is not defined as a set of scheduling practices (seven classes a day, five requirements and two electives), it is access to and support for all that is available to the overall student body. Therefore, a student with a disability who is enrolled in a school that requires two units of community service credits *must* engage in

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Lt. Joseph P. Kennedy Institute

Innovation and Leadership in Developmental Disabilities

If you are looking for a challenging career move, we have one for you. The Lt. Joseph P. Kennedy Institute is conducting a nationwide search for a Senior Director to oversee its educational programs, including a self-contained special education school serving as a transition site into seven satellite school programs practicing inclusive education, a federal grant to build capacity of the Washington, D.C. public schools to include students with severe disabilities, and a similar grant from the Archdiocese of Washington to promote inclusion in Catholic schools.

Requires doctorate in education, special education or related field, extensive knowledge of best practices in special education and school inclusion (elementary and high school), experience consulting with school systems, ability to oversee and guide a complex set of programs into the next century. Ideal candidate will have national reputation and credentials as a researcher/educator who can establish relations with universities, foundations, government agencies for research, student training, internships, and other collaborations.

This is an excellent opportunity to join an innovative organization committed to leadership in the field of developmental disabilities. The Kennedy Institute offers an excellent salary and benefits package.

Qualified candidates should submit their resume, with salary requirements to:

Kennedy Institute
801 Buchanan Street, N.E. • Washington, D.C. 20017
Attn: Tia Plunkett, Director of Human Resources

The Institute also accepts resumes year round for the following positions:
Inclusion Consultants
Special Education Teachers
Disability Specialists
Positions require Masters level degree in Special Education or related area and minimum of three years experience working in an inclusive educational setting.

We are committed to diversity in the workplace and promote a drug-free environment.

The **National Council on Intellectual Disability** (NCID) web site will be relaunched on February 1, 1997. The site will be called "Disability Information and Communication Exchange" (DICE). It will have a new design and concentrate on bringing you the latest news and information about disability in Australia.

We encourage your critique of the web site and welcome suggestions for its continued development to enable NCID to better meet your information needs.

Visit our site at http://www.peg.apc.org/~ncid or contact us by E-mail at ncid@peg.apc.org

RESPONSE:

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educational activities outside of the school building. Conversely, a student who attends a school where all formal courses take place in the school building would participate in community activities only at times beyond the school day. (Like their peers without disabilities, students with disabilities would acquire skills for adult life through after-school and summer jobs, volunteer service, and leisure pursuits.) (Tashie & Schuh, 1994). McDonnell contends that this strict adherence to what is typical runs counter to the special education process (IEP teams determining individualized schedule/placement). He asserts that "full inclusion is uniquely personal and varies significantly from one person to another." It is with this belief that our opinions diverge. We believe that by defining inclusion differently for each student we risk a rapid descent down the slippery slope toward the same old definition of "the least restrictive environment" (remember the continuum?).

As long as access to the mainstream is controlled by IEPs, placement teams, regulations governing teachers' roles, and the debate about benefits and rationale, students with disabilities will continue to be excluded on the basis of "individual need." We must shift our energy from maintaining separate programs and curricula to working with our general education colleagues to make the mainstream a welcoming and effective learning environment for all students. ■

ASSISTANT PROFESSOR

Tenure track position available in the area of Special Education/Early Childhood, Department of Special Education, University of Utah. Responsibilities include teaching graduate courses, conducting field-based research, supervision of graduate students, collaboration with faculty in other departments in training professional educators, serving on department, college, and university committees, and collaborating with local, state, and national agencies and organizations.

Qualifications include an earned doctorate in special education or closely related field by September 15, 1997. The candidate is expected to have a minimum of three years of experience in educational service programs for children and youth with disabilities, including (a) experience in augmentative and alternative communication systems and strategies; and (b) expertise in meeting the communication needs of children/students with disabilities from different linguistic and cultural backgrounds. Experience with transdisciplinary teaming and collaborative implementation of communication interventions in general education, home, and community settings is strongly preferred. The candidate is expected to have the ability to teach graduate courses in these areas, and interest and experience in field-based research, with preference given to individuals with experience or skill in multi-method research.

For a copy of the complete position announcement and required application materials, please contact Valori Miles at (801) 581-8121. Application materials must be postmarked by March 15, 1997. The start date for the position is autumn of 1997.

The University of Utah is an AA/EO employer and encourages applications from women and minorities, and provides reasonable accommodation to the known disabilities of applicants and employees.

The University of Utah
Master of Science Degree Program
COMPREHENSIVE BEHAVIOR SPECIALIST

The Department of Special Education at the University of Utah is pleased to announce a new interdisciplinary program to promote the professional development of educators and related servers who work with children and youth with significantly challenging behavioral needs. The focus of this 2 1/2 year program are those professional competencies (i.e., functional analysis, program development, implementation, team facilitation, training and technical assistance, and evaluation) needed to provide positive support to students in neighborhood schools and inclusive settings. Graduate students will apply each of these skills across the different levels of service planning encountered by professional team leaders or consultants – individualized support, classroom-based and/or school-wide systems, multi-agency and community based planning, and multicultural adaptations and modifications.

The Department is now recruiting interested students for Fall 1997 admission. Stipends are available for eligible candidates. For more information on the program or admissions process, contact either Dr. Richard Kiefer-O'Donnell at (801) 581-3080 or Dr. Robert O'Neill at (801) 581-3989.

TRANSITION COORDINATOR AND PH.D. PROGRAM.

Lehigh University offers a unique Ph.D. program with opportunities for funding. Current position available as transition coordinator. For more information contact: Dr. Diane Browder, Lehigh University, A319 Iacocca Hall, 111 Research Drive, Bethlehem, PA 18015, or phone (610) 758-3267. Application deadline is April 1, 1997.

COORDINATOR: Personnel Preparation Program for the Education of Children with Vision and Multiple Impairments.

Pennsylvania College of Optometry, Institute for the Visually Impaired, Department of Graduate Studies in Vision Impairment.

Qualifications: Advanced degree(s) and Certification of Education of Visually Impaired Students, and 5 years teaching students with visual impairments required. Doctorate, additional certifications, expertise in low vision, successful grantsmanship skills, service delivery across age ranges, and experience with distance education strategies preferred.

Roles and responsibilities include administration, teaching, supervision, grant proposal preparation, and team teaching. New grant supported program that includes both on and off-campus site responsibilities. Start date ASAP, salary commensurate with experience.

Send, fax or E-mail letter of interest, vita and supporting documentation to: Dr. Kathleen Mary Huebner, Assistant Dean, Graduate Studies in Vision Impairments, Pennsylvania College of Optometry, 1200 W. Godfrey Avenue, Philadelphia, PA 19141, (215) 276-6093; Fax (215) 276-6292; E-mail KATHYH@PCO.EDU

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on language "that emphasizes the humanity of people with handicaps." Terms such as "the autistic," "the retarded," and "the severely handicapped" refer to characteristics, not individuals. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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TASH Newsletter

VOLUME 23 ISSUE NUMBER 3 MARCH 1997

REFLECTIONS OF TASH

A Collection of Inspiring Articles

1986 *to* 1996

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"I had been told at one time that TASH was an organization of extremists. I thank God for the extremists of TASH. I am proud to be a member.

I congratulate Frank Laski, Nancy Weiss, and all the great pioneers and members of TASH on more than two decades of creative and aggressive responsibility to the sacred value of individual human life.

You of TASH have provided courageous cutting-edge leadership, magnificent initiatives that have given millions of Americans with disabilities the potential to move from institutions, poverty and welfare to productivity and community.

From independent living, IDEA, and deinstitutionalization, to supported employment, supporting living, assistive technology, self-advocacy and the historic ADA, you have led the way. Your passionate, principled creativity has enlarged the lives of millions like me.

We love you and are with you all the way. Lead on!"

— Justin and Yoshiko Dart

"TASH is an important point of connection for people who are interested in individuals who have been labeled disabled. There are a number of organizations that have an interest in some single aspect of the support and advocacy picture — family support groups, education or employment advocates, lobbyists, research institutes, and so on. But inclusion is about all of us — with our different points of view, self-interests and experiences — getting together and working things out together with a profound respect for diversity.

TASH is a structure that offers us the possibility of discovering and practicing this respect for diversity. This role is essential if all of us are to fulfill our dreams for and with the most vulnerable people in our society."

— Judith Snow

"No organization existed prior to 1975 that believed that children with severe disabilities were capable of learning skills beyond current knowledge. Many thought these children were best left as a low priority in all aspects of community and education.

TASH became the leading organization advocating for integration of students with disabilities in the late 1970s and early 1980s.

TASH created a balance between advocates, parents, and professionals. Now, as then, TASH continues to be at the forefront of the fight for justice, equality, and empowerment for all individuals."

— Ed Sontag

"In the time in which we live, TASH is a critical and essential 'life saving' organization. Cutbacks, cynicism, and all the other "-isms" must be countered. TASH is a critical piece of that response team.

TASH is the embodiment of the power of the dream to create a world where 'All Belong!' Personally and professionally, we need TASH to carry forward its mission with vitality and without compromise.

There is a proverb which says 'Without a vision, the people perish.' We say 'Without a TASH, the people will perish.'"

—Marsha Forest and Jack Pearpoint

"It is impossible to overestimate the importance of TASH as an organization. The policy and advocacy role that TASH has played over the decades to represent those who cannot speak for themselves has been momentous.

TASH advocacy has affected the lives of millions of others when — against all the combined "wisdom" of the profession — TASH took stands to say: everyone can learn, everyone can be included, everyone has something to say and needs a way to say it AND no one deserves to be punished (or killed) because of an attribute that we call handicap. TASH as an organization and each of its loyal leaders and members can be justly proud of the role that TASH has played in these matters.

For twenty years TASH has built its well-deserved reputation on risk. Let us not stop now. Let us continue to inspire the field. Let us lead special education, rehabilitation and human services into the next millennium with creative new approaches to understanding and serving labeled people. It is our reason for being and our best hope for the future."

— Anne Donnellan

FROM THE EXECUTIVE DIRECTOR

BY NANCY WEISS

Welcome to this collection of some of the thought-provoking articles that have been published in the TASH *Newsletter* over the last ten years. Although we had room for only a handful of articles, we felt it was time to recall some of the great contributions to TASH's history. If you already are a TASH member we hope this glimpse back offers both a reminder of how far we have come and motivation to maintain energy for continued change.

If you are new to TASH, this issue will give you a good sense of what TASH is all about. TASH is not a parent organization, a professional organization, or an organization of self-advocates; rather, it is a true coming together of people with disabilities, parents and other family members, advocates, professionals, students and researchers from around the world. TASH does not focus on a single area of concern; we are not about education, early childhood, family issues, community living, supported employment, recreation, or facilitated employment. We are an association made up of people who, collectively, are interested in all of these issues and more.

What ties TASH members together are our values — values which demand opportunities for all people to live, learn and work in communities that include, challenge, engage, and value children and adults with disabilities. TASH believes that all families and individuals deserve the right to direct their own lives. Our mission is to eliminate obstacles that prevent equity, diversity and quality of life. If you see your values reflected in the statements above, you need to be part of the TASH movement for social justice. We need your voice - now, more than ever.

A TASH membership allows you to stay informed about policy matters that will directly affect people with disabilities and their families ... issues such as school and community inclusion, managed care, employment, and full participation in family, school and community life. These are the kinds of issues we keep abreast of so we can keep you informed as promising new practices are developed and public policy changes are proposed.

As a member you'll have opportunities to hear about the most progressive and exciting work being done internationally in the areas of inclusive education, supported living, self-advocacy, family issues, early childhood, communication, employment, specialized health care, positive behavioral supports, multicultural issues, recreation and leisure, related services, higher education, and more.

If you share our values and vision: diversity, equal rights and inclusive communities for all, join with us and have a part in shaping the future for people with disabilities and their families. As a member you'll receive:

- TASH's monthly *Newsletter*. The *Newsletter* is full of the information you need to stay abreast of events in a changing political environment. The provocative articles provide information about the very latest developments in the disability field and will challenge you to re-think some of the toughest issues affecting people with disabilities, their families and advocates, today.
- As a national member, you'll also receive our critically acclaimed Journal of the Association for Persons with Severe Handicaps (JASH). JASH is the premier vehicle for the dissemination of progressive research in the disability field. The Journal carries more articles on topics such as inclusion, facilitated communication, supported living, self-advocacy, early childhood, positive behavioral practices, disability rights and issues of concern to families than any other publication available.
- Finally, as a national member, you'll receive substantially reduced rates to attend regional workshops and the annual conference. Join disability advocates, parents, self-advocates, and leaders as they gather each year to meet and exchange ideas and information on every aspect of inclusive communities for children and adults with disabilities. The spirit and optimism, the unbeatable combination of personal experience and professional expertise, and the tremendous wealth of information and enthusiasm make this the conference of choice in the disabilities field.

If you are not a current member, I urge you to use the form on the back cover of this issue to join TASH today. When you do, we'll rush you your first issues of our publications and more information about membership benefits. We need you in our ranks because people with disabilities need the kind of advocacy TASH provides now, more than ever.

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TASH (The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

Building communities in which no one is segregated and everyone belongs;

Forging new alliances that embrace diversity;

Advocating for opportunities and rights;

Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

Supporting progressive legislation and litigation; and,

Promoting excellence in services.

EDITOR'S NOTES

This month's issue marks a departure from our standard, topical format. Throughout the years, the *Newsletter* has contained numerous reflective, innovative and cutting-edge articles on a variety of topics. These articles have served to inform and inspire many of us. Equally important, however, the *Newsletter* has served as a vehicle through which dialogue, challenge, and change have emerged.

It is always a good idea to periodically return to our "roots" to re-visit people, places and issues of interest and importance; to re-charge our energy, enthusiasm and efforts; and to re-affirm our collective commitment to the critical tasks before us. This issue of the *Newsletter* affords each of us an opportunity to engage in such reflections.

Join us as we take another look at the hard-won victory of Rachel Holland, her family and supporters (page 21). Re-visit Judith Snow, the Joshua Committee and their circle of friends (page 11), and remember once again TASH's extraordinary friend, Ed Roberts (page 39).

The power of self-advocacy and the right to exercise individual choice is conveyed in articles by John O'Brien, SABE, and Norm Kunc (pages 9, 18, 27), while Justin Dart, Ed Sontag, Judy Heumann, Anne Donnellan, and others reinforce why now, more than ever, an organization of the strength and dedication of TASH is needed (pages 2, 39).

Also look for outstanding informational resources such as Mark Partin's "10 Steps to Full Inclusion" (page 15), Lucyshyn, Horner and Ben's article on positive behavioral supports (page 31) and Doug Biklen's commentary on the facilitated communication debate (page 36).

Although we were able to include only a limited number of articles, we hope you find this issue to be of particular value, as it's sure to become a TASH "collectible!"

— Priscilla Newton, Editor

WHOM DO I CONTACT??

- **For issues of policy, chapter or committee support or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
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- **For information on membership, permission and reprints, newsletter advertising, or publication/video sales, call:** Priscilla Newton, Director of Member Services, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the newsletter or to make a submission, call:** Priscilla Newton at (410) 828-TASH, Ext. 102.
- **Don't forget to visit TASH's web site at http://www.tash.org**
- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230, e-mail: lgoetz@sfsu.edu

The TASH Newsletter is available on audiocassette for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail: pnewton@tash.org.

Who are they and what do they want?
— An essay on TASH —

BY LOU BROWN,
UNIVERSITY OF WISCONSIN-MADISON
SEPTEMBER 1990, VOLUME 16, ISSUE 9

People often ask why we have TASH. Don't we have enough organizations? Is there really a need for a separate group of people to represent people with severe disabilities? Why are TASH people so ideological and demanding? Don't they realize they are running into windmills? Why don't we put our resources behind those with more potential?

We have TASH because in the late 1960s and early 1970s it was abundantly clear to a few parents and professionals that no other organization was addressing the ideological, research, financial, and programmatic rights and needs of people with severe disabilities; the most vulnerable, segregated, abused, neglected, and denied people in our society. The people who were quarantined in horrible institution wards; who were excluded and rejected from public schools by too many of the continuum tolerators; who were confined to segregated activity centers and workshops; and who were quarantined in nursing homes and other unnatural living environments that were certified as acceptable by the ruling professionals.

In the early days of TASH we often wondered, if professionals are going to devote their careers to people with severe intellectual disabilities; if mothers, fathers, brothers, and sisters are going to spend enormous energies and resources over long periods of time fighting for basic services; and if legislators are going to be pressured to pass much needed legislation and to secure extremely important tax dollars, what is it that we want?

Initially, we wanted a ramp, more speech or physical therapy, someone to clean a catheter, money for research, service delivery model development and personnel preparation, a summer school program, and other isolated components. It soon became obvious that we should want the highest possible quality of integrated life for 24 hours a day, 7 days a week, 365 days a year for people's lifetimes. We started to dream that persons with disabilities should have all their resources, longitudinal support, respect, dignity, legal protections, and other phenomena necessary to be the most that they can be, to experience a humane existence, and to make meaningful contributions to their communities in accordance with their abilities.

Specifically, we started to strive for the healthiest possible bodies; opportunities for all children to grow up with non-disabled friends, neighbors, brothers and sisters; a society in which all people live in decent, family-style homes; the resources and support necessary to perform real work in the real world; and access to the richness and variety of heterogeneous local communities, including becoming involved in the same recreation\leisure environments and activities utilized by non-disabled others. In short, we wanted integration and the resources necessary to realize and enjoy it.

Conversely, we also realized we did not want aversive conditioning, denial of medical treatment, disabled-only schools, institutions, organ harvesting, workshops, enclaves, group homes, retarded camps, Special Olympics, and other manifestations of segregation and de facto inferiority.

If that was the dream, what was necessary to approximate realizations? Several factors were considered critical at the time and seem at least as important today. First, we needed a penetrating, thought-provoking, constantly evolving cluster of values that would show us where to go and guide our way, get us through the rough spots and keep us focused on our targets. Values transcend individuals. They must be abstract, ideal, and pure. They must be scrutinized and evaluated in relation to their real and potential effects on the lives of people with disabilities, not on the people who expound them. Values should be enthusiastically discarded when they are no longer healthy or helpful and we should demand more and better from their replacements.

Second, we realized that the individuals we were attempting to serve were the most difficult to teach, the most challenging to render autonomous, and the ones who needed extraordinary assistance and support to realize reasonable personal fulfillment. The extant intellectual wasteland was unacceptable. Thus, one of the more consuming and enduring activities of TASH was, and still is, to use all the energies and resources necessary to convince talented, productive, effective, committed, and ideologically sound young people to pursue a wide variety of careers serving individuals with severe disabilities.

TASH never has been, and hopefully never will be, an organization that exists for its members. We are not a trade union. We are not interested in a group life insurance policy, a deferred annuity program, a tax-avoiding getaway vacation attached to the conference, or any other divisive, diluting, or distracting irrelevance. We can get all the above and more elsewhere. TASH exists to help people with severe disabilities and their families live the best possible lives. All we do should be referenced against that quest and anything that interferes should be resisted and resented.

Third, we knew that if we operationalized the best possible services

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WHO ARE THEY AND WHAT DO THEY WANT?

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conceivable in 1970, they would be embarrassingly inadequate. Thus, while we should always revere and respect that past and those who created it, we realized that we had a moral obligation to relentlessly pursue a better future. This commitment to new and better values, concepts, and practices often pit professional against professional, pit family member against family member, and converted friends, and colleagues to enemies. It still does. Some said let them die; we said no. Some said harvest their organs; we said no. Some said lock them up; we said no. Some said shock, beat, squirt, and tie them; we said no. Some said activity; we said work. Some said custody; we said access.

Fourth, and perhaps most important, we knew that we needed to join those few parents who were outraged by professional acts of commission and omission; who truly believed their children deserved more; who had the courage, will, and tenacity to challenge existing authorities; and who had the intelligence and insight to see through the mush and get to the heart of what was good for their children.

TASH learned some important lessons from some of the many mothers and fathers who did not plan to have a child with severe disabilities, but did. They were told to send them away, lock them up or accept what was. They did not. They devoted unbelievable amounts of energy, creativity, sweat, money, time, and love to the betterment of their children. In most instances, it was not their children who benefitted from their efforts, but all those like them who followed. We all owe tremendous debts of gratitude, continuous expressions of appreciation, and unbounded respect to these relentless, fantastically effective and creative mothers and fathers.

Who were Burt Blatt, Bill Bricker, and Marc Gold? They were some of the great early professionals of TASH who made wonderful differences in the lives of people with severe disabilities. They were people of vision, intensity, intelligence, wit, commitment, and charm. They were some of the rare geniuses who guided us in the early days—who made us believe that all people could learn, that all people had the right to live in decent homes, that no one should be abused, and that inclusion is better than exclusion. We cannot call them anymore and we cannot see them at the conference, but their spirits still move us.

Who are Tom Gilhool, Dick Cohen, David Shaw, John MacIntosh, Reed Martin, Frank Laski, Stan Eichner, Bill Dussault, David Baker, Orville Endicott, and Harvey Savage? They are some of the many lawyers who have expended substantial proportions of their professional lives trying to ensure that one third of the government of the United States and a major portion of the government of Canada—the judicial system— work for the most legally denied. They made Pennsylvania stop excluding children from public schools and start closing its institutions. They convinced the courts of the United States and Canada that **all means all** and that a person with disabilities is not one-half, three-fifths, or seven-eighths of a citizen. It is hard to imagine where we would be without these tough, brilliant, and remarkably effective legal Don Quixotes.

> ***TASH exists to help people with severe disabilities and their families live the best possible lives.***

Finally, if we have learned anything at all over the past 20 years, it is that there are some aspects of a person's life that we have no right to compromise. We cannot negotiate the size of an institution; no one should live in one. We cannot function on a committee to determine who does and who does not get medical treatment; everyone does. We cannot debate who should get an integrated education; all must. Just because we are overwhelmed, frustrated and at a loss for something to do, we cannot tolerate shocks, slaps, pinches, or any other obnoxious violation of dignity. Let the moderates, compromisers, and data worshippers go elsewhere. Let the people of TASH be value based, unbending, tough, aggressive, assertive, graceful, compassionate, and effective.

Have no doubt that the people, allies, values, and experiences of TASH have accomplished much over the past 20 years. Have no doubt that much more must and will be done. Twenty years from now cars will be safer, cancer and AIDS will be cured, racism and sexism will be in our past, acid rain will be conquered and, if we do our jobs, people with severe disabilities will live productive, safe, healthy, happy and integrated lives.

Editor's Update:

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Critical Issues is a TASH-produced book containing contributions from more than 70 renowned TASH supporters. *Critical Issues* was published shortly after this article appeared in the TASH *Newsletter*. The book continues to be a classic in the field.

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Thoughts about Self-Advocacy

BY MICHAEL KENNEDY, WITH BONNIE SHOULTZ

APRIL 1996, VOLUME 22, ISSUE 4

I give quite a few talks around the country on self-advocacy. Most of those talks are to service providers and parents, although there are some people with disabilities in some of the audiences. One thing that amazes me still is that although self-advocacy has been around for a long time now, since 1974 at least, there are some people who don't know anything about it. When I talk about it, they have a really surprised look on their face like it is a whole new world. Most people are very open to hearing about it, and I get requests to send more information about it from the people in the audiences. In this article I will talk about some things I want people to know about self-advocacy.

> ...THERE IS ALWAYS A RISK FACTOR WHEN SOMEONE IS MAKING CHOICES FOR THEMSLEVES, BUT PEOPLE STILL NEED THE OPPORTUNITY, EVEN IF THEY MAKE A MISTAKE.

Here is what Self Advocates Becoming Empowered*, the new national self-advocacy organization, believes about self-advocacy.

We believe that people with disabilities should be treated as equals. That means that people should be given the same decisions, choices, rights, responsibilities and chances to speak up to empower themselves, as well as to make new friendships and renew old friendships, just like everyone else. They should also be able to learn from their mistakes like everyone else.

The self-advocacy movement was started by people with disabilities, especially people who had been in institutions and state schools, because they wanted their basic rights like everybody else. But before they could exercise their rights, they had to fight for the right to be heard and to have choices in their lives. They had to find out what basic rights they had, and then they had to begin to teach other people with disabilities, parents and service providers.

Self advocacy is for everyone. Some people say to me, "It is fine for you to speak for yourself, because you aren't as disabled as my son or daughter, or the people I work with." I disagree with them. I say, "Have you taken the time to learn what that person wants or might need? Has the person heard about their rights? Is he or she facing an issue they need support with? What can the person say for himself or herself, and how can you help him or her express more? Or are you just assuming that they want what you want for them?"

A lot of times I find that people have not taken the time to ask, and have just assumed they knew what was best for the person. I had one parent say to me one time that she always made the decisions because it was easier than figuring out how to help her daughter communicate. I said to her that I didn't know what her daughter's disability was, but there had to be a way that she could actively participate in the choices about her life.

> WE ARE SAYING THAT WE SHOULD HAVE REAL CHOICES, NOT JUST THE CHOICES THAT OTHER PEOPLE GIVE US.

The first thing they would have to do is figure out a way for the mother and daughter to communicate with each other. Next would be to try to discover how the daughter could learn more about the choices she has, and then how she could make the choices. The daughter could be supported to make an informed choice of some kind, even one the mother might not make or feel totally comfortable with. This wouldn't have to be a big choice. We know there is always a risk factor when someone is making choices for themselves, but people still need the opportunity, even if they make a mistake.

When people tell me that I am "higher functioning" than the people they are talking about, I feel like they are telling me that I don't have anything in common with other people with disabilities. It's like they are putting me in a whole different category and saying that I don't have any right to speak. It upsets me because I take it that they don't want to give anyone else the opportunities I have been given, and that what I say can be ignored because they see me as more capable. It is a way of dividing us and putting down those who have more severe disabilities or who haven't had the opportunities to experience different situations in life.

Instead, they should be looking at how much each person would be able to offer if they were just given the chance to voice their wants and exercise their rights. For example, I recently visited a group home and heard a staff person say, "How do you like the way I decorated the house? The manager said I could do whatever I want." That told me that the residents didn't have a say in how their home would be decorated, when they could have been involved in planning and picking out the decorations. This is a simple example but who knows how things would look if the residents had helped with the decorating? And how will those residents learn to make other decisions if they can't be involved in how their home looks? I don't think she had even thought about involving them.

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THOUGHTS ABOUT SELF-ADVOCACY

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Later on she said to me, "We give choices." But even if that is true, it leaves the staff people in control.

The self-advocacy movement is here to say that things must be different. We are saying that we should have real choices, not just the choices that other people give us. Real choices means having the chance to choose the same things that other people, who don't have disabilities, have. No more and no less. Changing the words you use to refer to things is not enough. Calling everyone with a disability a self-advocate, or saying that everyone is given choices, are examples of just changing the words. To me, being a true self-advocate means being an active participant in a self-advocacy organization, speaking up for yourself, and making sure that your wants and needs are understood and valued. It also means understanding your responsibilities as a member of this society.

Self-advocacy has become popular, to the point that it has become a buzzword that people use without really knowing much about it. Some of the dangers of that are that agencies can use the word to make themselves look good, or that people will pick a select few of us to be on every committee, to give testimony, and so on, without looking for other people with disabilities who might have something to contribute. Then they can say that they have consumer involvement, without really having it, because the same "consumers" are doing everything.

Another danger of not really understanding self-advocacy is that people outside of the movement, like parents or agency representatives or public officials, tell us what self-advocates should be doing. They are always saying, "You should testify about this," or "you should be working on that," without realizing that we need to decide for ourselves what we should be working on and how much time we can spend on what we choose to do. It is hard for us because most of us have been taught that we should please other people, not disappoint them by saying no. Often the advisors (these are people without disabilities who support us in our self-advocacy work) have to help us set limits and see that it is okay to set our own priorities.

The self-advocacy movement is international. There are organizations in Britain, Australia, New Zealand, Canada, Sweden, and other countries. There is a new book about self-advocacy all over the world, and I recommend it highly. It is *New Voices: Self-Advocacy by People with Disabilities*, edited by Gunnar Dybwad and Hank Bersani, Jr. It has chapters by people from each of the countries that I mentioned. They talk about their philosophies of self-advocacy, in their own words, and about its history in their countries. There is a whole section on the United States, but I believe it is also important to see how people in other countries think about it.

The common thread, to me, is that people with disabilities want a fair shake in life. We want the same things as everyone else. We don't want our lives controlled by systems and the people who work in them. We know that everyone has to follow some rules, but it is impossible to have a meaningful life if you are always controlled by other people. I recently wrote a chapter on self-determination (Kennedy, pp. 45-6) where I talked about this issue in depth. I will quote some of the part where I gave suggestions:

> *"The system... needs to support the idea of teamwork and power sharing between people and their helpers. The system also needs to support the idea that people should be able to live how they want to, even if the professionals would live differently. The system is there to assist, offering guidance but not threatening us if we don't take the advice. This always means listening to us, really listening, and giving us feedback that is honest but respectful."*

People involved in the self-advocacy movement help each other to advocate for things like power-sharing and system change. As a movement, we work on broad goals, like closing all the institutions in the country, but we don't forget the individual person with a disability who has problems in his or her own life. We support each other as much as we can, and because of this we have learned many lessons about listening and speaking up.

**To learn more about or to join Self-Advocates Becoming Empowered, write to them at P.O. Box# 121211, Nashville, TN 37212-1211.*

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REFERENCES:

Dybwad, G., & Bersani, H. Eds. (1996). New voices: Self-advocacy by people with disabilities. Available through Brookline Books, P.O. Box 1047, Cambridge, MA 02238-1047. $29.95 Telephone 617-868-0360.

Kennedy, M.. Self-determination and trust: My experiences and thoughts. In D.J. Sands 6 M.L. Wehmeyer, Self-determination across the lifespan: Theory and practice, pp. 45-46. Available soon from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624. Stock X 238X, approximate price $35.00. Telephone 1-800-638-3775; fax 410-337-8539.

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PRINCIPLES FOR DEVELOPING INDIVIDUALIZED SUPPORTS

BY JOHN O'BRIEN

APRIL 1995, VOLUME 21, ISSUE 4

Assist people with developmental disabilities to develop their individual abilities and personal interests.
Assisting personal development requires learning effective ways to collaborate with the person, a person's family, and others who know and care about the person to set goals that are individually meaningful. Service providers must learn to negotiate a balance between safety and comfort and the risks associated with learning.

Discover and respond to individual choices.
Responding to individual choice calls for increasing flexibility in the use of available staff time and funds and decreasing investment in activities, service settings, and programs that are inflexible.

Support important personal relationships and encourage positive participation in community life.
Supporting relationships entails a responsibility to promote a caring community by the ways in which service providers present people with disabilities, invite community involvement, and hire and employ community members and spend money in local areas. Relationships with family members and friends offer an irreplaceable source of continuity, identity, and protection.

Deal effectively with people's vulnerabilities.
Dealing effectively with vulnerabilities means that each person will have an individually defined safety net that offers reasonable protection from harm and that identifies a responsible service provider. Abusive and neglectful conditions and disrespectful behavior by service providers are always unacceptable.

Promote personal and organizational learning which leads to continual improvement of service provider ability to meet these four essential contributions.
Because everyone involved in providing services is responsible for assuring and improving quality, managers have an obligation to insure that people have adequate opportunities to understand the mission and principles that guide service provision and adequate training to carry out their responsibilities competently.

Like other citizens, people with developmental disabilities find security and joy in the love of family and friends, meaning in contributing to community life, pleasure in participating in interesting activities, and personal development in the search to discover and develop their talents and abilities. The life-long need for competent assistance with the individual effects of disability and the pervasive effects of prejudice make people with developmental disabilities especially vulnerable, and this vulnerability is often compounded by the effects of poverty, community breakdown, and discrimination based on cultural differences.

Committed respect for the dignity and rights of each person with a developmental disability requires willingness to get to know and respond to each person as a changing individual. The way to gain this vital knowledge is to attend carefully to each person's interests, preferences, and choices, and to join each person in creating positive opportunities to pursue them. Some people will challenge our ability to understand their interests and choices, and some people will challenge us to understand and respond to their positive potentials despite dangerous or difficult behavior. But by far the greatest challenge to the current service system is utilizing available resources in ways that respond effectively and flexibly to each person's individual requirements for assistance in assuming their responsibilities as a citizen and as a community member.

Offering people with developmental disabilities decent living conditions and reasonable opportunities calls for significant learning and major change at every level of our service system. We must contend with:

- massive past investment in programs and administrative structures whose mission was to oversee and control groups of people with developmental disabilities;
- rapid growth in knowledge of how to best serve people with developmental disabilities;
- the large scale of our service system as a whole and the size and organizational complexity of many service providing agencies;
- feelings of helplessness at the magnitude of our task, or cynicism about our capacity to deal with the conflicting interests that shape our services, or pessimism about our capacity to recruit and retain decent and able people to provide services.

To continually improve our capacity to support people with developmental disabilities, we commit ourselves to the disciplined application of the following questions to all of our activities from assisting people with their daily routine to long range planning for the service system as a whole.

If we are disciplined in applying these questions, we will identify problems worth solving and solutions worth implementing. Over time, the people who work in our system will be able to point to a credible, public record of learning about how to do their job in ways that safely expand the opportunities available to people with developmental disabilities. In consequence of this learning, we will steadily increase investment in activities that prove effective, and discover growing satisfaction on the part of people whose expectations for themselves are rising.

How does this activity increase our capacity as service providers to assist people's development?
Assisting personal development requires learning effective ways to:

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- collaborate with a person, a person's family, and others who know and care about the person to set goals that are individually meaningful;
- offer understandable information about new possibilities;
- support people to try new experiences;
- promote access to good health care;
- deliver needed professional services in ways that are not coercive and that intrude on every day life only as much as is necessary;
- promote access to decent housing;
- promote access to a reasonable level of discretionary income;
- negotiate a reasonable balance between safety and comfort and the risks and discomfort associated with learning.

How does this activity increase our capacity as service providers to discover and respond to individual choice? Especially important are a person's choices about:

- where to live and with whom;
- what work or other meaningful activity will structure the day;
- what leisure and recreational pursuits will add enjoyment to life;
- how necessary personal assistance and professional services are provided;
- when and how daily activities and routines are carried out.

How does the activity increase our capacity as service providers to support important personal relationships and to encourage positive participation in community life? For many people with developmental disabilities, relationships with family members offer an irreplaceable source of continuity, identity, and protection. Some people with developmental disabilities can also count on their friends.

To support these relationships, service providers learn to:

- offer needed assistance in ways that support rather than taking over important relationships;
- help people to reunite when family or friends have lost contact;
- play a constructive role when a person with a developmental disability is in conflict with a family member or a friend.

Participation in community life offers benefits as well as important developmental challenges. To promote participation in community life, service providers learn to:

- assist people to identify and make contact with community activities of personal interest;
- help people find ways to overcome barriers to participation such as problems with transportation, fears about unfamiliar situations, lack of skill in welcoming a person with a developmental disability, or concerns about adequate adaptation or assistance to allow participation;
- assist people to make satisfactory use of the same services as other people in their communities do.

How does this activity increase our capacity as service providers to deal effectively with people's vulnerabilities? Abusive, neglectful, shoddy, or disrespectful behavior by service staff is always unacceptable. But the more a person depends on the performance of service providers to meet basic needs, the greater must be provider concern for effective management of risk.

Increasing the capacity to deal with vulnerability requires continuing effort to:

- strengthen relationships that embody respect for each person's dignity and regard for each person's rights and responsibilities as a citizen so that people who provide services are worthy of trust;
- strengthen the voice of people with developmental disabilities and their families and friends so that they can identify unacceptable conditions without fear of further harm;
- clarify the duty of every person employed to provide or administer services to notice, report, and take positive action to deal with abusive, neglectful, or dangerous situations;
- identify potential risks to people's safety or freedom and implement measures to minimize these risks or to respond to dangerous or restrictive events should they occur (at the individual level, this means identifying dangerous situations and intervening to avert or minimize harm; at the agency and regional level, this means insuring the availability of skilled people and flexible funds to support necessary interventions);
- creatively resolve conflicts in situations that are emotionally charged.

In consequence of these efforts, each person will have an individually defined safety net which offers reasonable protection from harm. A named service provider is responsible for insuring and documenting that there is a reasonable capacity to respond to the risks that each person faces.

How does this activity increase our capacity as service providers to continually improve our ability to assist development, respond to choice, strengthen important relationships, and deal with risk? Because everyone involved in providing services is responsible for assuring and improving quality, managers have an obligation to insure that people have adequate opportunities to understand the mission and principles that guide service provision and adequate training to carry out their responsibilities competently.

People with developmental disabilities and their families play a critical role in identifying strengths and weaknesses in service provision, in problem solving to improve quality, and in advocating for more effective and flexible services. Their satisfaction with service providers' ability to help them to define and achieve personally meaningful goals is the fundamental measure of success. In order for them to play their role effectively, people with developmental disabilities and family members need accessible ways to register their judgments and participate in defining and solving problems, and understandable ways to learn about how services should work for them.

Managers have a responsibility to promote openness to learning by reviewing and continually improving practice. In many cases, this means leading a cultural change.

This is a summary of principles developed by John O'Brien based on discussions at a conference sponsored for the State of New York Office of Mental Retardation and Developmental Disabilities by the Center on Human Policy, Syracuse University in July, 1994.

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Friends circle to save a life

BY ROBERT PERSKE
JANUARY 1988, VOLUME 14, ISSUE 1

The following article was taken from Bob Perske's speech at the Annual Meeting during the October TASH Conference.

Last year, at the TASH Annual Meeting in San Francisco, a few speakers made a disquieting observation. They said that persons with severe disabilities may have good family support and community programs, but most still have a painful empty space in their lives because they don't have any friends.

They raised these questions: Can persons really be integrated into the community if they do not have any friends? Is there something a good friend can do that family and human service workers cannot? Should TASH see friendships between ordinary citizens and persons with severe disabilities as a leading edge?

Many TASH members felt strongly enough about the issue to write programs for getting so-called normals and persons with disabilities together. I have collected enough of them to fill three fold-up file boxes.

But what about friendships?

Friendship is a familiar but illusive term. Alfred North Whitehead, in *Science and the Modern World*, shows how familiar things are the hardest to research (1957, p.6)—like friendships. Some of us, of course, do need to cut back to classifying, counting and analyzing relationships or social interactions (e.g., with relatives, with human service workers and with ordinary citizens). But I think some of us need to draw values from the larger, more radiant term. Otherwise, as Whitehead believes, our research will degenerate into a medley of ad hoc hypotheses, truncated findings without a philosophical base (1957, p. 25).

Families provide things that friends cannot. We need childhood nurturing, a place in a family history, birth-to-death ties that are strong.

But friends help us stretch beyond our families. Social scientist Lillian Rubin, in *Just Friends*, shows vividly how we turn more to friends that family when we seek to be affirmed as adults (1986, pp. 15-33).

Human service workers do things that friends can't. When a team is at its best, it can focus on a specific problem, draw up an orchestrated plan, then the workers in unison, work for a healthy goal.

Jack Pearpoint and Marsha Forest with Judith Snow

But friends help us move beyond human service goals. Friends provide us with myriads of options that could never be programmed.

Friends help us rehearse adult roles. You and I are the way we are largely because we rehearse actions and attitudes with friends—things we wouldn't even think of trying with family or paid professionals.

Friends serve as fresh role models. We often choose the friends we do because we see something in them that we wish for ourselves.

Good friendships are a mystery. There is no ritual or individual program plan contract for starting them. They thrive and fade. They end without celebration, certificate, plaque, funeral or divorce decree.

Good friendships are attractive. Others watch them with great interest. Letty Pogrebin, in *Among Friends*, says, "Friendship is like sex: We always suspect there's some secret technique we don't know about." (1987, p.5).

Friendships generate their own energy. Quite often, when two people take to each other, the zest and successes they develop equal much more than the sum of two people's efforts.

Friendships become a haven from stress. When things get tough, many of us have good friends "on call."

Spouses and committed couples can be good friends. When a couple cannot, their commitment is in trouble.

Friendships are reciprocal. Both parties receive some kind of enrichment from the relationship.

If a person is breathing, he or she needs a friend. So say many TASH members with special interests in friendships.

People in authority often frown on friendships. According to C. S. Lewis in *The Four Loves*, "Men who have real friends are less easy to manage or 'get at;' harder for good authorities to correct or for bad authorities to corrupt" (1971).

Friends can demystify strange behaviors. While visiting two friends working together in a print shop in Rockville, Maryland, I saw one friend—during a moment of boredom—begin moving his arms and fingers in patterns which professionals call "autistic." When I asked the other friend what he thought about such movements, he replied, "Hey man, if you think that's weird, you should come with me to the tavern I go to on Friday nights."

Human service workers cannot program friendships. They can, however, set up frameworks in which they can happen.

Every friendship is unique and unrepeatable. What happens in each relationship sets it apart as vividly as

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human fingerprints do.

One can learn much from good friendships. A good friendship can become a "living document," something from which we can draw leading-edge values for our field. The following story makes the point:

Judith's story

Toronto, Ontario: The first time we met, it took only a second before I looked past the motorized wheelchair and the rotary switch she operated with her right thumb—the only thing she can move below her neck. Judith Snow's deep, warm voice and her kind, round face, with just the right touch of redness in her cheeks, suddenly made me feel I was one of the most valuable people in her life. I looked into her eyes to see if she was for real, and I saw a graciousness and an intensity that made me feel she was. Later I knew these eyes had seen more battles in her short lifetime than I'd probably see in two long ones. People know her as a no-nonsense woman, capable of describing a complete situation with a single metaphor of cutting through ambiguous issues to what is really right and wrong. Judith possesses emotions so honest and so free, she could have danced on tables. But sometimes I catch my breath when I think about a human service system that would have surely killed her if it hadn't been for a precious circle of friends.

With a chuckle, Judith told me she came into the world in 1949, in the General Motors town of Oshawa, Ontario, "coming off the assembly, like a Monday morning product." Others must have thought so, too, judging from the many attempts to fix her severe muscular dystrophy as if she really were a car.

- Physicians attempted corrective surgery in her first year of life.

- At age 10, steroid medications only succeeded in dropping her soprano voice to a deep bass.

- At 13, she underwent two unsuccessful sterilization attempts using radiation treatments. Medical personnel decided against the third because it could have killed her.

- Later, an unsuccessful back operation cost her the use of her arms except for that single thumb, and she developed a constant pain in one leg.

- Physicians predicted that she would be dead by age 30. And when doctors predict. . .well, people do pay attention. After all, here was a person who scooted all over town in her motorized wheelchair, but when she was out of it, she depended totally on others to handle her basic needs for staying alive— her bathroom needs, dressing, eating, getting in and out of bed—things we take for granted. And when people failed to do these things carefully, she paid the price in added pain. For Judith, improper care could even kill her.

Public school served as an obstacle course, too. Her parents, rejecting all pressures to institutionalize her and believing she had a contribution to make to society, moved to Whitbe, Ontario, thinking she could get a better education there. Then, when she was 12, the district refused to keep her in school. So the family moved to Pickering, Ontario, where the school accepted Judith. There, her grade average climbed from a C to an A.

As for friends, she didn't have any, and she was kept away from places where she could have made them. "I learned to be a disabled person," she said. "You don't expect people to be your friends. You have a shell. And so I worked three or four hours a day on homework. It became a psychological defense."

Then came growing days at York University in Toronto with the government providing the much needed attendant care. In this environment, she moved in her wheelchair from class to class—all over metropolitan Toronto, too. She soared academically, winning bachelors and masters degrees and an academic achievement award, as well. But most important, here she suddenly began refusing to be everybody else's project, to be an "always compliant crip" with everyone else making choices for her.

At graduation, in 1976, things looked bright. But no one dreamed how many unfeeling, rule-worshipping government functionaries lurked in her future, ready to block her and sometimes knock her flat.

After graduation, her school related attendant care program dropped away. All attempts to get this much-needed support from other agencies failed. There were no funds available for this type of disability, they said.

At the same time, Judith founded the University's Center for Special Services for Handicapped Students, and since she had already demonstrated natural skills as an advisor and advocate for others with disabilities, she became the Center's first director. She often did the work of two people on the job, but her salary fell far short of an able-bodied professional's pay, making it impossible for her to cover her own much-needed attendant care.

She applied for housing and assistance at a community residence she helped found. They rejected her for being too disabled.

When all attempts to get attendant care failed, she moved into a nursing home. And so, during the day, she exuded the perky strength of a counselor to students in crisis. Then she returned each evening to the nursing home, where staff members viewed everyone as sick—or belligerent. Because she returned after supper, her meal consisted of a cold peanut butter sandwich. And since care for her other physical needs was slipshod, too, Judith suffered repeated bouts of bronchitis, skin rash and stomach bleeding. She weathered them all and kept going.

Then the nursing home owners asked her to leave. "They felt they weren't making enough money," she said, "even though I was gone all day. They said I was too sick to live in a nursing home."

Judith moved to a chronic care institution where the common denominator rules of the wards were ingrained in staff members. She had to pay a private nurse to get her up, bathed, dressed and nourished, so she could get to work on time. Then, because a good night's sleep was impossible on the ward (many of the women screamed at night), she paid for a semiprivate room. "I paid for the privilege

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of living with a 102 year-old woman who called out loudly for nurses all day, ' she said, "but not at night, thank God."

At the same time, Judith's skills as a teacher had developed until professors asked her to lead class sessions and workshops on the political and social aspects of disability—even though her own political and social situation continued to diminish. The cold meals, staff members' inability to render regular, careful care— especially getting her to the toilet as often as she needed—slowly beat her down until she landed in the general hospital suffering from malnourishment and influenza.

When she became well, she begged human service workers not to send her back to the institution. She asked for an alternative situation—anything where she could get the attendant care she needed. They found nothing. They returned her to the institution.

But she went back fighting. She demanded warm meals and the right to bathroom help when she needed it. She managed to get a physician to write it out as an order.

Her new plan failed. All the regular aides evaded her and worked with other people, and only those who could not speak English were assigned to her.

As exhaustion approached again, a campus physician allowed her to move into a university residence for two weeks for a rest. She paid for attendant care, using meager savings to hire students.

After two weeks, she couldn't face going back to the institution. So she moved into a friend's hallway and continued to use her salary to pay students to help her. She thought she only had to 'get by' for five months because she had been promised a spot in an apartment building with a brand new attendant care program.

Later, the government official who made the promise reneged. The new rules stated that anyone needing more than three and a half hours of attendant care could not be served outside of the institution.

On March 6, 1980—four days before Judith was scheduled to help lead a provincial workshop on understanding people with disabilities—she collapsed. One colleague described her mental condition as "just like falling into a black hole." She suffered total exhaustion. Another colleague heard her say, "I can't go on . . . I can't ask anyone, anymore, to do anything else for me." After that, she spoke little and sometimes incoherently. It suddenly became clear to her colleagues how hard Judith had been working simply to stay alive. Then came a letting go. It happened when she was 30 years old.

A circle of friends

Judith Snow would have gone down for good if it hadn't been for five people who circled around her, almost like firemen preparing to catch a falling body in a net: Peter Dill, Sandi Gray and Peter Clutterbuck of the Canadian Association for Community Living and Marsha Forest and Jack Pearpoint of Frontier College. Ironically, all worked as educators or human service workers, but none of their agencies—no matter how high-sounding their goals—could help this woman with such acute needs so quickly. Therefore, the five quickly took off their professional coats and hats and came together around Judith as a circle of friends. Here is what happened:

Peter Dill, the convener of the workshop in which Judith was to have been a speaker, first learned of Judith's condition. He called Marsha Forest. They gathered up Judith, took her to Marsha's home and put her to bed, where she stayed down for a week. Marsha and Dill called an emergency meeting on behalf of Judith. Fourteen professionals and students attended.

Marsha, without talking about mental breakdown or physical exhaustion or letting go to die, began the meeting in her clipped, optimistic manner. "Look, people, I need Judith, ' she said. "I need to get her back to work again." She explained that what Judith really needed was her own home and her own attendant care. Immediately, the circle came up with an emergency plan of donated time and money to get things rolling.

Two days later, when Judith began talking and gathering her strength, the five gathered around Judith and began long-range planning. They listened to what Judith wanted in life, and they did not think it was unreal for her to have a home and love and a professional pursuit like themselves. They taped large pieces of paper on the wall. On them they listed funds available and funds needed, developed a roster of paid and volunteer attendant care persons and they brainstormed about how to get the existing human service agencies to respond to Judith's real situation. Judith, moved by what her friends had done, dubbed them the "Joshua Committee"—people who knew how to break down walls. When the meeting ended, Judith's support system seemed stable. But nobody knew, given Judith's needs, how long they could keep it that way.

During the next month, the Joshua Committee spent almost every moment of free time on what it described as an impossible mess. And yet, each person now stands out for a separate piece of action he or she undertook:

- Sandi became the round-the-clock coordinator of attendant care, and when there was a gap, she filled it herself.
- Peter Clutterbuck became the exacting builder of budgets that could work, and he worked on proposals for raising money.
- Peter Dill found an interim apartment. He also served as the quiet, intuitive one who believed that five folks like they could gather together and mysteriously generate a power much more than the sum of five. He was right.
- Jack Pearpoint confronted the administrator of Ontario's Ministry of Social Services in a public workshop. Again, the workshop was to have included Judith, but she was still too ill to attend. Pearpoint called the official's attention to an empty chair on the platform, the one intended for Judith. He spoke about her condition and the promises the human service agencies had made but never kept. The official promised in public the special care funds she needed. Later,

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he could not recall his promise. So the committee called a press conference— before which the official's memory came back—and the press conference then served as an occasion to thank the official for his brilliant management of the whole affair.

- Peter Forest, having become a close friend earlier, was the tough but loving cheerleader for the whole process—hustling here and hustling there, paying attention to every detail, pointing to new directions, and even screaming at folks.

- Judith became the sixth member-in-full-standing of the Joshua Committee because the others encouraged her to take control of her own support system as it fell into place. It was her choices everyone decided to honor. Able-bodied people would never choose for her again! And so, she too, became a lusty chooser. She even learned to scream at the members. There has been lots of screaming at Joshua Committee meetings during the past seven years.

Joshua Committee influence spreads

Today, the Canadian Government recognizes Judith Snow as a leading expert on the political and social situation of people with disabilities. As a consultant for the Canadian Association for Community Living, she travels the continent with well-trained, caring attendants, and she works long hours on behalf of others with disabilities. She calls herself a "portable visionary who tries to show others how to encircle a person in crisis." She lives in a simple apartment in a trendy Toronto neighborhood. She can often be seen scooting around in her motorized wheelchair on the streets surrounding her apartment— greeting people as they pass; stopping to talk to others. It is safe to say she now has hundreds of friends and colleagues who have interacted or collaborated professionally with her.

The government pays for the attendant beyond what her own salary can afford—which comes to one half of what the government spent on her when she lived in an institution. Interestingly, the money must be sent to Frontier College, which has a mechanism for disbursing the money to her. (A government rule forbids the giving of cash to an individual—it can only give to human service systems.)

Joshua Committee members can document more than 100 successful circles that now function throughout Ontario. Each circle is unique and unrepeatable, and each member has applied the Joshua Committee experience in a different area.

Marsha Forest works in school systems, getting ordinary kids to encircle those with disabilities in the classroom. Peter Dill does it around families with members having a disability. Sandi Gray develops the same kind of circles in work settings, parks and recreational programs. Jack Pearpoint includes them in his beat-the street programs in Toronto's skid row. And Peter Clutterbuck has gone back to doing fiscal work, but he stands ready at the ring of a telephone to show how "successful circles of friends around a person with a disability can save governments thousands of dollars."

As for Judith Snow, she continues in her gutsy way to look into any situation where somebody is being pushed down or held back.

Also, the Joshua Committee's energy opened the way for many other friends to become involved, and in June, 1987, Judith announced her engagement to be married. See what happens when you give people choices?

Does the Joshua Committee still meet? They do, but sometimes they miss a meeting. The meetings are less messy now, and occasionally they are even boring. After all, Judith has more than five friends now—and she is in lots of other circles that take her time. But if a time comes again when a human service agency applies a mindless, unfeeling rule on their friend, the Joshua Committee will be back in business—fast.

Afterward

Judith Snow and the Joshua Committee—vivid living documents that they are—force us to look at three issues:

1. We in the human service business may become so preoccupied with developing, say, The Complete Area-Wide Drinking Fountain System, that we become paralyzed when one person, dying of thirst, suddenly comes to us and screams out for a single cup of water. After the person dies, we say, "What a pity. If only we had our service plan operating in time."

2. Most of us write programs that are perfect—on paper. They are like the football plays sports announcer John Madden draws for us during televised football games. Every player has an assignment, and if every man does his part, the play ends with a touchdown. The only trouble is that most plays do not end with a life. And I think most touchdowns come to team members who, after screwing up, have the guts and grit to get up off the ground and quickly try something else! Judith Snow's friends did not quit when their initial plans failed.

3. It is altogether possible for we human service workers to spend all of our productive years working with people having severe disabilities, and never know one as a close, personal friend.

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Inclusion in the Public Schools

STRATEGIES FOR PARENTS

10 Ten STEPS TO FULL INCLUSION

BY MARK PARTIN
MAY 1994, VOLUME 20, ISSUE 5

This was developed as a step-by-step guide for addressing inclusion at the IEP meeting and for developing a "paper trail" for use if an appeal is necessary to challenge a restrictive placement. The strategy itself is basically the same as would be used to address any other educational issue: the IEP process does not change. However, there are some strategies that can be used to strengthen your demand for an inclusive education program. Here are ten steps to get you through the process.

1. WRITE THE PRINCIPAL TO REQUEST AN IEP MEETING.

You can wait for your child's annual IEP meeting, or you can schedule a meeting apart from that. Request the meeting in writing. Address your letter to the principal of the school your child would attend if s/he didn't have a disability. In the letter, you will want to say that you are asking for an IEP meeting to review assessment information on your child, his/her progress on the goals and objectives of their IEP, and current placement. You also want to mention that, because you want the committee to start out with the assumption that your child will attend his/her neighborhood school, you are requesting that the meeting be held there and that instructional and administrative staff from the home school should attend. Be sure that the meeting is scheduled with lots of time allowed. This will be a long meeting— count on it!

2. GATHER REPORTS AND NOTES.

If you have any progress reports from other providers (private tutor, Sunday school teachers, medication reports from doctors), you should enclose copies in the letter requesting the IEP meeting. It isn't necessary to send copies of the letter to the Special Ed Director or the staff at your child's current school—because you want the school district to understand that the purpose of the IEP meeting is to consider placement at the home school.

Before the meeting, you must prepare! No amount of fancy talking or arguments at the IEP meeting will substitute for good preparation. You will want to review any testing reports that you have had conducted on your child privately, as well as any progress reports from supportive teachers —including his/her current teacher, if possible. You also should get letters or evaluations from any other people who have worked with your child in settings involving children without disabilities, such as Sunday school teachers or day-care providers, and confirm that some of them can attend the IEP meeting with you.

You may also want to put together some notes on how your child functions at home. This could include information about his/her attention span for tasks and activities enjoyed, participation in household chores and family activities, how s/he gets along with neighborhood children and relatives, and anything else you can think of that would give the IEP committee an idea of his/her community living abilities. Take a couple of days and just follow your child around and note the ways in which she/he shows independent living skills in the community. Perhaps s/he takes swimming classes at the YMCA; can answer the telephone and take messages; or actively participates with other children in the neighborhood. Maybe s/he cannot do many things without help, but can let a

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caregiver know when help is needed. The idea here is to show your child as someone who already has lots of skillful ways for interacting with others.

Remember to note how your child lets other people know what s/he needs and wants. Children who do not speak clearly often have ways of letting people know what they need. They may use sign language or gestures. Perhaps they can speak, but someone who doesn't know the child will have difficulty understanding them the first time—note how the child overcomes communication barriers, if any. Many school districts try to use communication difficulties as justifying exclusion.

The reason it is important to devote so much time to sharing observations of your child in community settings is that you are likely the only member of the IEP team who has an opportunity to observe your child outside the school setting. The two skill areas that are probably the most crucial in making an inclusive placement a success are behavior and communication. The term behavior is expanded here to include not only positive behaviors (like not hitting other children, or running away), but also independent living skills (being toilet-trained, for example). As for communication, we mean whatever system the child has devised to communicate wants and needs to caregivers who may not know them as well as parents. Children whose behavior does not present a physical danger to other students and who can let someone know when they need something are going to be among the easier students to include in regular programs. Students who present difficult behaviors should also have inclusive placements, but their IEPs must pay greater attention to the areas of behavior and communication.

3. MEET WITH THE TEACHERS.

It would be a good idea to schedule a parent/teacher conference with the current teacher as soon as you can, to find out which instructional and behavioral techniques are being used successfully with your child. If you can get a written description, so much the better— then you can present it at the meeting as an example of the kind of modifications that could be provided at the home school in general education classes to help your child be successful there.

4. TAKE THE WHOLE DAY OFF FROM WORK.

The IEP meeting will be timeconsuming if you force them to justify each portion of the IEP with assessment data and require them to justify all time that is not inclusive. If you've arranged to take the entire day off from work, you won't have to leave at a crucial moment when important issues are being determined.

5. TAKE WHAT (AND WHO) YOU NEED TO THE MEETING.

You really should try to have someone go with you to the meeting. If you have a friend or advocate who is going to attend the meeting with you, be sure to talk to them in advance about the goals of the meeting to ensure that you don't find yourself in the position of conflicting amongst yourselves at the meeting. If your child's other parent is going to attend, it is crucial to make a decision as to which parent is going to take the lead in discussing and interacting with the school at the meeting. This is not to say that both parents should not participate, but it is still a good idea for one person to take the lead in the meeting so that it is very clear that you, as parents, are presenting a united front to the school.

If you plan to tape record the IEP meeting, try to have a portable tape recorder that runs on new batteries and doesn't require plugging into an outlet. Take a notepad for writing your own notes of the meeting, and extra copies of any reports you want included in the minutes of the meeting.

6. GET TO THE IEP MEETING EARLY.

Get there a little early, so you have a chance to get yourself set up before it starts. Prepare your tape recorder to begin recording when the meeting starts. Pick seats so that there is not a clear division between you and the school district personnel. Put a teacher between you, or sit in a circle. When you arrange the various players, you can reduce the "us" and "them" factor in the meeting.

7. WRITE DOWN EVERYBODY'S NAME AND TITLE.

As soon as the meeting is convened, be sure that everyone at the meeting identifies him/herself and states what their position is with the school district, so you can write down each name, with correct spelling as the introductions proceed so you will have an accurate record—it may be impossible to read their signatures later.

8. ASK LOTS OF QUESTIONS/GET LOTS OF ANSWERS.

The next step is to review all of the formal and informal assessment information that has to do with your child's current placement. This includes the school district's most recent testing report, any progress reports from his/her teachers or therapists (including private professionals who have worked with your child), your information as a parent as to how your child acts at home, and any other information that might help the committee decide his/her placement.

After all of this information has been reviewed, the committee's next decision is to reaffirm your child's eligibility for special education. There usually isn't a lot of disagreement here. It really doesn't matter under which disabling condition a child receives services. A child with disabilities who is identified for special education is entitled to receive any and all services that he/she needs to benefit from school, regardless of the name of the disability.

Then, the IEP team assesses your child's strengths and weaknesses by reviewing his/her achievement on the short-term objectives of his/ her IEP and revises goals and objectives, if necessary. One of the areas that will be discussed is developmental skills or "adaptive behaviors" (independent living skills). This is the time for you to re-emphasize the skills and abilities you know your child has, particularly if your child is more independent at home than s/he is at school. It is not at all unusual for a child with disabilities to act very differently at school, especially if s/he has been in a highly segregated educational setting without many opportunities to demonstrate what s/he can do.

The IEP team will then need to look at your child's behavior management plan, if he or she needs one. Note the parts of the plan that would be able to be implemented in a less restrictive setting, like a regular class.

The next step will be determining the amount of time your child will spend in each of the curriculum areas, such as Language

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Arts, Math, P.E., Science, etc. Often children with disabilities are in special education classes for many, if not all, academics. *Some of the possible arguments that school personnel may use to try to justify a more restrictive setting are outlined below.*

9. SIGN THE IEP.

When it is time to sign the IEP, be clear about whether you are in agreement or disagreement with the committee's decisions. When the IEP comes around to you, be sure that you have the entire report in front of you before you sign it. This may sound obvious, but many times the signature page is passed around while a school district person finishes writing the notes on the rest of the report. You need to look over the entire report, including all of the minutes, before you sign, so you can be sure that all the major points of the discussion are written down. If they are not, request that it be done. Don't rely on the tapes of the meeting—they are sometimes not clear enough and are useful only as backup.

If the minutes are complete, but you are in disagreement with part or all of the proposed IEP and placement (including related services), then write out your points of disagreement on a separate piece of paper that will be included with the minutes.

10. GET A COPY OF THE DISTRICT'S COPY OF THE IEP REPORT.

If your opinion is one of dissent, after you have written it, read it aloud to the rest of the committee. Then sign the IEP and make clear that you are not in agreement with the committee's decisions. Be sure that the copy you receive of the IEP is fully legible and clear enough to make copies from for future reference.

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SOME PRACTICAL SUGGESTIONS:

Answers to possible objections against inclusion:

"S/he is not on the same behavioral or academic level as same-age peers." **Ask what modifications, including reasonable modifications of the curriculum or the addition of a teacher's aide, would be necessary in those classes for your child to be successful.** What you will be looking for in the school district's statements are indications of a willingness to make any modifications at all. You will also be looking at whether the modifications they suggest are mere token gestures or really bonafide efforts to adapt the regular classroom to accommodate your child's unique educational needs.

"Modifications would be too extensive." (Not "expensive", just "extensive" — in that the modifications would detract too much from the activities in question.) **Ask for goals and objectives to be put on the IEP that will bring his/her behavior and/or academic levels to a sufficient level so that less extensive modifications of activities would be sufficient for him/her to participate with age-appropriate peers.** You might want to mention at this point that you are not asking that the school district modify the regular program beyond recognition or asking the teacher to spend all of her class time on your child to the detriment of the other students in the class.

"Modifications would be too expensive." (This is usually the argument that comes up when a child needs an "extra set of hands" in the classroom — like a teaching assistant or when architectural modifications are needed.) **Ask how the needed modifications could be used by other students. For the teaching aide, ask whether the school has ever assigned an aide to assist the general education teacher, i.e., not assigned to a student one-on-one.** This helps to spread the expense over lots of children. Most children who need modifications (like an aide) can share the extra resource with other children in the classroom. It is a rare child who needs an adult assistant in constant attendance every minute of the day. Aides can typically be assigned other duties that benefit many other children in the classroom and in the rest of the school.

Since many children need a personal assistant only during certain scheduled times of the day — getting lunch going to the bathroom, or going out to the playground— decide what specific times an assistant would be needed. For classroom time, however, he/she may not need any extra help at all, particularly if the district has made some creative uses of adaptive or assistive technology,. For other children, a teaching assistant during "core" academic times for one-to-one or small-group instruction may be where the need is.

Questions you should ask:

Other questions you should ask the district are **whether they think your child could benefit from being in regular education for part of the day. Ask them to consider goals that are not just academic but also goals that have to do with age-appropriate language and behavior models.** If the IEP does not yet address needs such as language development, behavior, and socialization, then this is the point in the meeting to **ask for those and ask that they be implemented in a regular education environment.**

Although they will probably be addressing this all along, you may want to **ask the school district to be clear about what "harmful effects" that they would see your child presenting from placement in the regular classroom** (this is part of the reasoning that the courts use in considering placement). If they are discussing, at this point, the disruption that your child would have on the class, you should **ask them what effect they think the provision of supplemental aides and services would have in reducing this effect on the class.**

If the school says that your child would take so much of the teacher's attention away that the teacher would have to ignore other **students** to attend to your child, you should **ask if a teaching assistant or a teacher's aide could minimize the burden on a teacher.**

If the determination is, then, that your child must receive most of his/her instruction in special education, then you should **ask the school district to consider other regular education academic classes, nonacademic classes (such as art, music and P.E.), and interaction with typical children during lunch and recess. Ask what extracurricular activities have been considered for integrating your child with children who don't have disabilities.**

The last basic decision of the IEP team is at what school to implement your child's program. They may say that the only school where this program is offered is another school and that there is not an appropriate special education class at the home school. You should **ask at this point why such a class cannot be made available for your child and the other children in the home school's attendance area who need this kind of placement.** Inquire as to how many children in the area are being transported to another school that could benefit from a class at the home school — it's possible they don't have any idea, but ask the question anyway.

WHAT WE WANT

BY SELF-ADVOCATES BECOMING EMPOWERED, THE NEW SELF-ADVOCACY ORGANIZATION

BY RICK BETTS, BONNIE SHOULTZ, AND RUTH MARIE BECKWITH

FEBRUARY 1995, VOLUME 21, ISSUE 2

In September, 1991, at a national self-advocacy conference hosted by People First of Tennessee, the participants voted to form a national self-advocacy organization that would be a coalition of state and local organizations and would be governed by a Steering Committee made up of two people from each of nine regions of the country. The Steering Committee has been meeting since 1992 to establish the organization, write by-laws, file for tax-exempt status, and implement its goals.

In 1993, the Steering Committee received a grant from the Joseph P. Kennedy, Jr. Foundation to develop a position paper on community living. This paper, which includes the organization's beliefs about leadership, housing, relationships, respect and image, was completed in April, 1994, and was presented in July to national leaders inside the government and from major organizations. Excerpts from the paper, which represent the perspectives of self-advocates about the issues that affect them most, are included in this article.

COMMUNITY LIVING IS IMPORTANT TO US FOR THESE REASONS:

- People should not be put away
- To learn to become independent
- People can contribute to the community by work, projects, friendships, voting, paying taxes, etc.
- To help people have self-esteem
- To teach others how to work with people with disabilities
- So people can learn how to communicate with people
- To learn to share ideas and support each other
- So other people can learn about people with disabilities
- To show people who we are and what we can do

BEING LEADERS

What have we learned?

- It's important to step down and give other people a chance. If they don't do it how will they ever learn?
- Stepping down...It hurts some inside because it's hard to let go of something you helped start.
- People really use good judgment to elect the right people. We should support people to be on other boards and committees but we should make sure they're connected with a self-advocacy group.
- In order to be a leader, people need to listen to the grassroots.

What are ways people can help us?

- To know that it's good when self-advocates ask for help. To let people know they shouldn't have to struggle.
- Invite us to important meetings.
- Let us do things on our own, let us make mistakes and learn. To just be there, and we'll ask for help when we need it.
- Help us work through big problems.

What do we want?

- Opportunities to have good leaders as role models.
- Support so our voices can be heard and understood.
- THE PEOPLE SHOULD LEAD!
- People to accept who we are; respect and know what we stand for...to be strong and have a voice to where no intolerance stands in the way.

EXPERIENCING RELATIONSHIPS

What have we learned?

- It's hard. It takes two people.
- Communication is important. There are a lot of ways to communicate (don't have to be able to talk).
- Working with friends is good because of common interests.
- Just like everyone else...we want to date, get married, have opportunities to meet people.
- It is important to date someone who understands our disability.

What are ways people can help?

- Parents can talk about sex.
- Help people to communicate
- Help people feel safe and that you can be trusted so they can confide if they need to.
- Create opportunities to meet people.
- Counseling should be available.

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What do we want?

- To be believed.
- To be treated like everyone else.
- More protection.
- Not to be put into (disability) boxes.

BEING RESPECTED

What have we learned?

- Listening to people shows respect.
- Staff are often the people who label most.
- We should be able to make mistakes like everyone else.
- When you learn more about self-advocacy, people expect more of you, sometimes too much.

What are ways people can help us?

- Staff can help create a positive image.
- Staff should teach people with value and respect.
- People can volunteer to help self-advocacy groups.
- Advocacy organizations should hire people with disabilities.

What do we want?

- Respect!
- Everything!

HAVING A HOME

We have learned:

- I like my own apartment better.
- Some staff are afraid of self-advocacy, afraid that people are going to become independent and stand up to them.
- Get people out of institutions, help them to be independent.
- Staff changes a lot. This is hard and it makes me mad. I worry about what the next staff person will be like.

What are ways people help us?

- People come by and see if I need anything.
- People take time to explain things to you so you can understand and make decisions (doctors, social workers).
- They follow-along people after they come out of the institutions.

What do we want?

- A home of my own.
- Friends you can trust.
- Choices in where to be.
- Safe place to live.
- Close institutions.

A case for teaching functional skills

PRESTON LEWIS

DECEMBER 1987, VOLUME 13, ISSUE 12

It is not uncommon to find instances of curricular content for students with moderate to severe handicaps based primarily on information derived from the administration of norm-referenced evaluation instruments. A dilemma often results when an attempt is made to translate test items failed at particular levels or mental ages into actual tasks to be taught. Not only were these evaluation tools never intended to be used in this manner, but the result is that students end up spending a majority of their school day being taught skills that are totally artificial and/or extremely age-inappropriate. There is no time or justification for devoting instruction to teaching items that are selected from a developmentally-based hierarchy of supposed "prerequisite" skills. A scenario of the outcome for one such student is portrayed below.

My other brother Daryl

Daryl can now do lots of things he couldn't do before!

He can put 100 pegs in a board in less the 20 minutes, but, he can't put quarters in vending machines.

Upon command he can "touch" nose, shoulder, leg, foot, hair, ear; but, he can't blow his nose when needed.

He can do a 12 piece Big Bird puzzle with 100 percent accuracy;

Though, he prefers music, he was never taught how to use a radio.

He can now fold paper in halves and even quarters; but, he can't fold his clothes.

He can sort blocks by color; but, he can't sort clothes; whites from colors for washing.

He can string beads in alternating colors; but, he can't lace his shoes.

He can tell me the names of all the letters of the alphabet when presented on a card; but, he can't tell the mens' room from the ladies' room when we go to McDonald's.

He can identify with 100 percent accuracy 100 different Peabody Picture Cards by pointing; but, he can't order a hamburger by pointing or gesturing.

He can walk a balance beam frontwards, side-ways and backwards; but, he can't walk up the steps or bleachers unassisted in the gym to go to a basketball game.

He can count to 100 by rote memory; but, he doesn't know how many dollars to pay for a $2.59 McDonald's coupon special.

He can put the cube in the box, under the box, beside the box and behind the box.

But, he can't find the trash bin in McDonalds and empty his trash into it.

He can sit in a circle with appropriate behavior and sing songs or play "Duck, Duck, Goose;" but, nobody else his age in his neighborhood seems to want to do that.

I guess he's just not ready yet.

BEST COPY AVAILABLE

The Art of Growing INVISIBLE ANTENNAE

BY NICOLA SCHAEFER
SEPTEMBER 1996, VOLUME 22, ISSUE 9

In a plane heading for Toronto, where I was to be part of a conference on inclusion of people with disabilities in their own homes within the community, I found myself talking as one does on planes, with a fellow passenger. We were both middle-aged women with adult offspring. Ellen told me about hers and then it was my turn.

"My youngest, Ben, is a tree surgeon in England; next up is Dominic, who's a freelance photographer in Vancouver, and my oldest, Kate, is a teacher in Winnipeg."

"Oh, yes," said Ellen, "What does she teach?"

"She's not a conventional teacher," I said. "But I suppose one could say she teaches the art of growing invisible antennae." Before Ellen's baffled expression had time to become permanent, I explained further. I told her what an interesting and complex woman my daughter is and how despite, or rather because of, the inconveniences with which she has to contend - including quadriplegia and lack of speech - she is, indeed, a brilliant, full-time (if unpaid) teacher to anyone willing to learn.

As her first student, I told Ellen it took me a while to adapt to her teaching methods. There were no lecture notes to be taken, no essays to be written, no exercises to practice, no books (beyond the generic "Cerebral Palsy: How to Deal with your Wonky Kid" type) to study. There was, and still is, just this lovely person lying or sitting around and challenging me to help her have a life.

Anyone unable to move much, or to communicate beyond body language, needs to have enormous patience when trying to get their point across. So, too, does the recipient of the information. So one of the first things I learned from Kate was to slow down when I was "listening", and to try first one thing and then another, and another, until I felt I had understood her. Consequently, I also learned to watch her expressions carefully to see what made her demonstrate different emotions. These emotions included amusement (the trigger for which might be me dropping something on my foot and hopping around cursing, for example), alarm (the approach of a nurse with a needle or a baby brother looming over her with a Tonka truck), dreaminess or contentment (particular pieces or types of music, having a massage), interest (when she was young it was usually food, but when she became a teenager this was superseded by hairy young men), irritation or disdain (being encouraged, sometimes with the necessity of force, to intake fluids when she wanted simply to be left alone), and pure joy (the appearance of a favorite person, perhaps).

> *"Self-advocacy . . . is a natural progression. Over the past decade there has been a consensus among professionals to create programs that take into consideration the individual needs of people with disabilities. It's obvious if you start with the individual, then individuals need to learn to speak for themselves."*
>
> *Gunnar Dybwad*

A major lesson I've learned in life with Kate is the importance of becoming an advocate on her behalf. Originally a shy person who accepted the status quo, I gradually realized that Kate had rights and needs that weren't being addressed, and wouldn't be unless I got together with the other parents and, with them, spoke up for our children. Back in the 1970s, when there was literally nothing to assist parents like myself and our children - integrated school, respite care and so on were but dreams - I remember saying to a friend, "I'm constantly putting up my hand at meetings, typing proposals, phoning bureaucrats; I'm becoming nothing more than an irritant." "Remember," said my friend, "irritants create pearls" referring, of course, to the grain of sand in the oyster that is the beginning of the pearl. It was a good thought.

Nicola Schaefer is a writer and speaker from Winnipeg, Manitoba, Canada.

Testimony of Robert Holland

SUMMER 1995, VOLUME 21, ISSUE 7

TASH Board Member Speaks to U.S. House of Representatives

My name is Robert Holland. I live in Sacramento, California where I am the father of Naomi who is one week old, Hannah who is two years old and Rachel who became a teenager June 21st.

Our family survived a five year legal battle with the Sacramento City Unified School district over Rachel's right to a regular education classroom placement instead of the special day class for the severely disabled which has been the standard placement offered by our school district. Not unlike other parents who have children with or without disabilities, we are simply crazy about our children. However, in defending Rachel's need and right for inclusive education in court, we came to understand Rachel even more—how she learns best, what slows her down, what motivates her, how critical her friendships are and how capable and hard working she is given greater opportunities for learning. However, as the case progressed, it became more and more clear that we were simply fighting for Rachel's childhood, ironically in a district whose motto is "Kids First." Not unlike all parents of children with disabilities, we are trying to create a better future for Rachel, wondering all along what that future will look like. In large part our legal fight for inclusive education seemed the only way to make sure Rachel could be included in her community as an adult.

Despite three favorable court decisions which affirmed the regular classroom placement as the most appropriate for Rachel, the school district, in a last desperate act, appealed the case to the U.S. Supreme Court in April, 1994. Our attorneys, joined by the U.S. Department of Justice and the State Department of Education, asked the Supreme Court not to review the case. The Supreme Court agreed and on June 13, 1994, the Court denied the district's request for review—thereby affirming the lower court decisions upholding Rachel's right to a full-time placement in a regular classroom with the support of a part-time aide and special education consultant. While this wonderful legal victory ensures educational choices for all children with disabilities, what it meant for Rachel is that last fall without too much commotion, Rachel returned to public school at Leonardo da Vend School in the Sacramento City Unified School District where she has since been a member of a regular fifth grade class. While there is some room for improvement in implementing full inclusion for Rachel and the other students in her school and district, Rachel had a very successful year academically, physically and socially.

Rachel Holland

The final outcome, however, is clear and evident in her classroom, on the playground, in the lunchroom and on the regular bus she rides to school every day—Rachel is happy and progressing beyond anyone's expectations, most notably, the school district's expectations for her.

BACKGROUND ON THE CASE

Our legal battle with the Sacramento City Unified School District (SCUSD), began in 1989. Rachel was served for four years prior to that time in a special day class in the District beginning when she was in preschool. The problem began when we asked for minimal integration time for Rachel in the regular kindergarten room next door to her special day class. Recognizing the educational and social limitations for Rachel within a special education classroom, we requested a full-time placement in a regular classroom with support in the fall—an offer the district swiftly refused. Without even reading our detailed proposal, they claimed that their minds were made up and that nothing we could say would influence them otherwise. We soon appealed the school district's decision to mediation through the state hearing office, and placed Rachel in a regular kindergarten class in a private Jewish day school where she had gone as an infant and toddler. We really had no choice at this point. The structure of the segregated classroom, the intent of the district to use Rachel as evidence against herself, and the growing level of hostility left us with few options for Rachel's education. During the course of the hearing, the school district proposed a confusing split-placement for Rachel between a regular class and the special education class in a school outside

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of our neighborhood, and refused the assistance of state personnel trained in inclusive education. The District's proposed placement would have required Rachel to move between regular and special education "day classes" a total of six times a day.

In August 1990, a state hearing officer ruled in Rachel's favor, ordering placement in a regular education classroom with the support of a part-time aide and part-time special education consultant, finding that the school district had failed to make an adequate effort to educate Rachel in a regular classroom as required under the Federal Individuals with Disabilities Education Act (IDEA). The school district then appealed the hearing officer's decision in federal district court.

The federal district court decision issued by Judge David Levi in March, 1992 rejected all the arguments the school district put forth to exclude Rachel and affirmed the previous ruling by the state hearing officer. The decision is beautifully written—clear, strong and yet sensitive to the educational needs and rights of students with disabilities.

The Judge's decision is noteworthy because of the substantial weight he gave Rachel's regular classroom teacher, and to my wife's observations as a mother, in assessing the academic and non-academic benefits of Rachel's regular classroom placement.

Despite the strength and clarity of the federal trial court decision, the school district later decided to appeal the decision to the federal appeals court. In January 1994, the U.S. Court of Appeals for the Ninth Circuit affirmed the federal district court decision requiring that Rachel be placed in a regular education classroom full-time with non-disabled children. As if this signal from the courts were not strong enough, the school district decided in April, 1994, to appeal the case to the U.S. Supreme Court. The Supreme Court's quick decision not to hear the school district's appeal allowed all the lower court decisions to stand.

SO WHAT DOES THIS MEAN?

What all this means is that parents should no longer have to fight about whether their children with disabilities have the right to be included. Instead, we can now focus on how to include students with disabilities in our regular schools and classrooms—how to adapt the core curriculum, how to facilitate friendships, how to provide appropriate support services, etc. The long and short of it is that school districts can no longer make placement decisions based upon IQ or type of disability. The court in Rachel's case has reaffirmed placement in a regular classroom as the preferred and first placement option for students with disabilities. By reasserting this right, the courts have reassigned the burden to school districts to prove students with disabilities, according to the new court standards, cannot be included. This stands in sharp contrast to the practice of most school districts, which I call the "parole system of integration" where students are first placed in special classes and the burden has been placed on parents to prove that their child can be integrated or included in a regular classroom—or that the child has to somehow earn regular classroom placement.

The Necessity of Reimbursement

In many ways life for our family has improved since the case has ended. Rachel's return to public school has relieved a large financial burden grown over many years of private school where we paid for the classroom aide in addition to private school tuition and a special education consultant. Our attorneys' costs have been reimbursed, and we were fortunate to recover some of our private school costs. For now, we have paid our loans and accumulated debt for the most part, and have enjoyed putting out lives and our home back together again.

Sometimes I wonder what financial course our family might now be on had reimbursement not occurred. We would have a debt to the private school of $14,000; we would have a debt to our first private attorney, who helped us tremendously through mediation and fair hearing, of more than $32,000; and we would have personal loans of $12,000.

■

What all this means is that parents should no longer have to fight about whether their children with disabilities have the right to be included. Instead, we can now focus on how to include students with disabilities in our regular schools and classrooms—how to adapt the core curriculum, how to facilitate friendships, how to provide appropriate support services, etc.

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Had we not been reimbursed, our plans were to repay these debts by selling our house. We also needed to find a new home and relocate to a school district where Rachel would be welcomed into regular classes, even before we could expect to sell our home. We were unable to afford both the rental and the mortgage payment on the home at the same time. We were in a very bad position. Because we had already used a home equity loan, refinanced our home and were using the proceeds from the sale of our family business to pay for Rachel's private schooling, our housing costs have become high. I remember returning from work on June 13, 1994 to the home of my in-laws where we had been living since February as we were preparing our house for sale. When I heard the news that the case was over, I was in disbelief. When reimbursement finally came, I had just made the mortgage payment using the last available credit we had.

Had there been no reimbursement for the court costs of *SCUSD v. Holland*, we would have filed bankruptcy and watched the foreclosure of our home and accepted the lifelong responsibility of $62,000 in personal debts.

Had there been no provisions for the reimbursement of attorney fees, Rachel could not have even used her favorable hearing decision because we could not have kept pace with the district's appeals. We had used all of our savings on our private attorney, who had generously

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allowed us to delay payment. Luckily, we had been in contact with DREDF, The Disability Rights Education and Defense Fund. Without their help, we would have never been able to continue. Without the provision, they could never afford to help families like ours.

Had we been unable to pursue legal remedies during the constant appeals by the district, other families having children with disabilities would have to face similar adversities in the future. They would see that without the possibility of reimbursement for court costs, there could be no due process beyond the special education fair hearing process; it would be financially unattainable. In my experience, I have seen that school districts naturally enjoy many advantages. School districts have staff attorneys— parents do not. Districts have separate budget line items for litigation—families do not. Districts can also draw upon other staff and resources (in our case district staff spent between 2000 and 3000 hours)— parents do not have access to these public resources. Districts also have support services unavailable to parents such as professional, secretarial, lobbying and public relations staffs, and Xerox and fax machines. And perhaps most importantly, district personnel are paid during extended disputes— parents are uncompensated for their time and effort.

While the district had two staff working overtime for two months before the fair hearing, I was paying extra staff to cover time lost in my retail shop. In a school district, no board members or staff face the stress of financial risk in litigation; nobody will have to pay out of their pockets—regardless of the outcome. But parents do. My wife and I lost all of our sick leave and accrued vacation from our jobs during two mediations and 14 days of fair hearing, three days of federal district court trial, and numerous days involving IEP meetings, Federal court hearings, depositions and preparation of court documents.

To avoid prolonged, acrimonious and costly disputes with districts, many families simply move to another district. Others, such as single parents, just don't fight. Most commonly, parents trust the professionals unequivocally, because they believe through their experience, that their voice as a parent is not given value. The assessments seem so irrelevant and IEPs are made so complicated and long and distressing to endure, that a large number of parents don't even show up—especially when parents have to miss work or arrange costly child care. Alternative meeting times are rarely arranged because of teacher union contract requirements. While the role of the parent is highly valued in IDEA, school districts tend to discount and patronize or, if necessary, overpower parents in order to maintain control of the decision making process. In mediation we first were characterized by our district as being in denial of our child's disability, her "limitations and deficits."

In Federal Court, the District asserted that parents cannot really provide accurate input regarding their children because they could not be objective. Even after the Supreme Court's decision not to hear our case, the majority of Rachel's school board still believes, and one member has publicly stated, that "Decisions about education should not be made by parents, but by education professionals who know what is best for children."

I strongly believe that parents who question the routine services and placement decisions school districts make for their children and find the need to use the due process system, must have the promise of court cost reimbursement or their advocacy on behalf of their child will also be a route to financial ruin for the family.

It has been stated by school board associations that the manipulation of the special education laws by parents are robbing districts of money needed to teach other students. I want to remind you that more often it is the district who acts aggressively to manipulate the laws. The issue that took our family first to mediation, was one of integrating Rachel in afternoon recess. She had been kept out of recess for a year and a half without our knowledge. You should have seen how intensely the Sacramento City Unified School District worked to manipulate the laws in order to justify her being kept in, while her classmates/school played outside.

It is also argued, similarly, that a child like mine is robbing the system. While the school district claimed throughout the case that it would cost $109,000 a year to include Rachel in regular classes, Rachel's placement is probably saving money. She and another included student share an instructional aide and an adaptive P.E. teacher who benefit and assist all students as well. She no longer rides a "special" bus door-to-door, and may soon use a campus resource specialist rather than separate personnel to coordinate services.

I want to close by suggesting that the underlying reason of those wanting to eliminate reimbursement for attorney fees for families who prevail in special education due process is to maintain institutional authority over the education of children with disabilities, and has little if anything to do with money.

It is very challenging to raise a child with a disability. I neither deny her challenges nor am I unduly subjective about Rachel. I do honor her bravery and I do respect the time she needs to be understood because I know how much she wants to be part of the whole world and to relate and be understood by her peers of varied abilities. She tries harder and learns more when she is provided the opportunity and choice to be a member of a typical school environment We know this about her and cannot deny her access to it. And Congress in 1974 recognized and anticipated the need for checks and balances by the due process provisions it included in the law.

I have come this long way to testify to you today that when we had to use it, special education due process worked. I am trusting that this Congress, too, will understand and respect the IDEA's commitments to our family's choices. Without due process and the hope of reimbursement, individuals who have disabilities and their families would have very few educational choices, indeed.

Testimony of TASH Board Member Robert Holland to the Committee on Economic and Educational Opportunities Subcommittee on Childhood, Youth and Families, U.S. House of Representatives, June 27, 1995.

The Underachievement of Supported Employment: A Call for Reinvestment

BY DAVID MANK

JULY 1994, VOLUME 20, ISSUE 7

Even a casual review of the status of the national supported employment initiative shows that thousands of individuals are benefiting and that supported employment is offered by community programs in every state in the nation. Yet, despite these successes, access to supported employment is severely limited, the quality of the outcomes is challenged, and the investment in change appears to be dwindling. If supported employment for persons with severe disabilities is to expand and improve to meet the growing demand, then communities and government alike must analyze both the successes and the problems of the initiative and create a new path to change.

Supported employment is no longer a new initiative—more than a decade has passed since its inception, and hundreds of millions of dollars have been invested. In light of the implementation of the Americans with Disabilities Act, the Rehabilitation Act Amendments of 1992, and promising innovations in supported employment, now is the time to re-examine and apply the lessons of the last decade to needed policy decisions and reinvest in decent jobs for people with severe disabilities.

The satisfaction with, and successes of supported employment—though no less impressive and perhaps no fewer in number than a few years ago— appear to be overtaken by concerns about quality and unmet need. Expectations have been raised, but not fulfilled: access is limited, too many people work too few hours and earn very little income, many work in less valued jobs. Tens of thousands of people with severe disabilities interested in supported employment, are unserved. Investment in facility-based, segregated employment is not decreasing.

At the same time, remarkable innovations have emerged that have improved the basic notions of supported employment—natural supports in the workplace, assistive technology, person-centered and career planning processes, and a focus on choice and self-determination— and enhanced the promise and the potential. Although the local and individual level of implementation has unfolded with continuous improvement, national supported employment appears to be an underachiever: showing high quality in its selective demonstrations and innovations, but failing in the scope and quality of implementation.

SUPPORTED EMPLOYMENT'S ORIGINS

The supported employment initiative emerged in 1984 (Public Law 98-527) amidst the growing dissatisfaction with the unemployment and segregation of nearly all citizens with significant developmental disabilities in the country. Low wages or no wages, activity programs with little constructive activity, and mass segregation defined the context from which the promise of a national initiative emerged. In contrast, irrefutable reports emerged about the capabilities of people with significant disabilities to live and work successfully in the community.

In this context of dissatisfaction, the promise of a job in the community with individualized support for success for all persons with significant disabilities captured the imagination of a generation of people with disabilities, their advocates local practitioners and government officials. What emerged was an initiative on a nationwide scale with the ambitious objective of changing the entire system of day services—of virtually replacing unemployment and segregation with real jobs, for real money, in real businesses in the community.

TEN YEARS AFTER

Since those auspicious beginnings, a decade of investment and implementation have passed. More than 110,000 people have had access to supported employment and nearly $100 million has or soon will be invested in state systems change grants.

Federal funding of more than $40 million per year through state developmental disabilities or mental health agencies and more than 2500 community programs represent a considerable investment. Newsletters, professional publications, videotapes, conferences, training programs, seminars and forums have emerged. The Vocational Rehabilitation Act has been changed to include supported employment as a legitimate outcome. New forces of change—such as

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the notions of choice, careers, and inclusion—in a diverse workforce have replaced the early, and less than satisfying, focus on group sizes of eight or less and a mandated 20 hours a week of work. More importantly, the capability of people with significant disabilities to contribute in meaningful ways in the workforce has been demonstrated again and again in communities in every state and territory.

Currently, the available data about the expansion of supported employment clearly show that the rapid increases of the late 1980s have been replaced by little growth in the 1990s. While the uncompromising vision and stated goal since 1984 has been replacement of segregated employment and day services, in fact, little change has occurred in the total system of activity centers, day treatment centers, and sheltered workshops. The legacy of supported employment to date has not been a revamped system—rather, it has been added to the existing continuum of services.

A number of issues are generating the perception of underachievement:

Questionable Quality of Integration and Employment Outcomes.
Although supported employment outcomes are clearly superior to those of activity centers and sheltered workshops, they do not meet the broad lifestyle changes that were promised. Supported employees are less segregated than their peers in sheltered programs, yet the integration that has resulted has been more physical than social. In addition, the fundamental role of the job coach as a trainer for the individual and a facilitator of employment success is now questioned, with concerns emerging that job coaches might actually impede integration. Recent studies comparing supported employment outcomes with the employment expectations of the rest of our society reach the obvious conclusion that supported employees neither make enough money to change lifestyles nor live above the poverty line.

Dissatisfaction on the Part of Self-Advocates and Advocates.
Many individuals in supported employment and their employers express satisfaction about the outcome achieved in their employment. However, self-advocacy and advocacy groups have repeatedly called for faster expansion and improved quality for all persons that might benefit, including better access for several groups of people with disabilities whose expectations are unmet.

Limited Access for People with the most Severe Disabilities.
The initiative has been criticized for failing to serve those people with the most severe disabilities for whom it was designed. For a number of practical or financial reasons, those persons were passed over in favor of placing people with mild and moderate mental retardation. Despite supported employment rejection of the "readiness model", a recent survey of administrators of vocational programs suggests that as many as 60 percent of those responding considered individual "readiness" to be a major barrier to developing supported employment.

Barriers to Replacing Segregated Programs and Workshops.
The vast majority of rehabilitation facilities indicate they do not plan to convert all segregated activity to integrated and supported employment. The incentives for conversion provided by the waning state supported employment systems change grants are getting fewer and fewer. Lack of interest and the systemic barriers to real systems change have resulted in supported employment being merely added as one of an array of vocational options, with the predominant mode being segregation and sheltered work.

Continuation of the Continuum.
Beyond the lack of replacement of the segregated system, is the continuum of services that range from total segregation to full integration. Without an unconditional commitment to integrated employment and clear policy, the entire continuum continues to be legitimized.

Conflicting Policy.
The ADA, the Rehab Act Amendments, and the Developmental Disabilities Assistance and Bill of Rights Act state that integration and real jobs in the community are the policy of the United States of America. Nonetheless, segregation and sheltered work are also supported by federal and state funding and policy, simultaneously funding them to exist side-by-side with little attention to the fact that these policies compete for the same resources: programs not committed to integrated employment have little pressure to change and those committed to change have little incentive.

Slowing Pace of Expansion in Supported Employment.
The early and rapid pace of expansion from a few thousand persons to more than 110,000 individuals in supported employment has been replaced by a nearly flat trend line, with concern about whether states can maintain the current numbers. A decrease in the federal investment in systems change coupled with state budget crises nationwide are resulting in little or no expansion despite increasing demand.

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Innovations in Supported Employment. There can be little debate that the pace and quality of implementation of supported employment needs improvement. Despite this, the emergence of natural supports in the workplace—demonstrating the capacity of companies to include people with significant disabilities in their workforce—offers improvements in stability and quality in employment. Assistive technology in the workplace is improving "low-tech" solutions in job design and providing "high-tech" solutions for people with severe disabilities. Person-centered planning approaches are beginning to provide better methods for exploring choice and careers for individuals. Voucher systems which place much more control of services and finances in the hands of people with disabilities are being explored. In the present context, such innovations seem to raise expectations. However, rather than energize, these innovations exacerbate the discrepancy between what is available and what is possible, increasing the growing dissatisfaction with the current status of the supported employment initiative.

These eight points, while not exhaustive in summation of the status of supported employment, capture many of the broader effects of the supported employment initiative. The important juxtaposition that must be observed is the contrast between the quality of innovations and the failure to achieve broad change. If the mission of supported employment were solely to create and improve on demonstrations of quality employment for people with significant disabilities, then it can be considered a success. If the sole criteria for success were ongoing rapid increases in the percentage of interested people with access to supported employment, then the initiative would be considered a failure.

In combination, the supported employment initiative must be considered an underachiever: full of ideas, even promise, yet failing to achieve its demonstrated potential. The issue at this time is not the quality of ideas and strategies for individual level implementation—the issue is the quality and effectiveness of the strategies for systemic changes.

Editor's Update:

The complete manuscript of this article was published in the *Journal of Disability Policy Studies*, 5 (2) 1994. The *Journal* is published twice yearly by the Department of Rehabilitation, University of Arkansas, 346 North West Avenue, Fayetteville, AR 72701. For information, contact Kay Schriner, Editor at 501-575-3656.

The author of the article, David Mank, is now affiliated with the Institute for the Study of Developmental Disabilities (UAP) at Indiana University.

Hey Baby, what time you get off work?

BY RON RICHARDS

JUNE 1987, VOLUME 13, ISSUE 6

I don't know how to describe, in formal psychological terms, the exhilaration experienced at the moment people get off work. I'm sure a lot of data-based research has been done in this area. Maybe rats were kept in tight, dark, loud environments for weeks, then suddenly released into the light of day with a lot of EEG electrodes attached to their little heads. I do know that getting off work is a powerful experience for some people. I know that just the thought of getting off work can sometimes keep a person going for a full eight hours.

Bells ring in car plants to tell people to start work, to take and return from breaks, to go to and return from lunch and to let them know it's time to go home. No other bell has the impact of the 4:00 p.m. bell on payday Fridays. It signals the end of the day shift, the end of a week, another time card with a lot of time on it that will assure that the next payday will be a good one.

Sitting in my office one Friday looking down on Detroit's East Jefferson Street, watching hundreds of U.A.W. men and women literally running out of the Chrysler Corporation complex, I came to know about the emotional power inherent in getting off work. People who had just spent eight hours moving around in slow-motion, suddenly became Olympic class sprinters, covering the two or three blocks from the gate to their cars in record time. Men who could hardly move their 270 pounds around during the day were magically able to leap snow banks and fences like white tail deer.

So, getting off work is a powerful experience, but before you can get off work you have to have a job. Today I drove Louis to his first day of paid work. When he got into the car the first thing he said was, "My lady just called me." I said, "Is that right?" Louis said, "Yea, she said, 'Hey baby, what time you get off work?'" He said, "I told her 4:00."

We both knew he really got off at 3:00 and we silently knew that getting off work is so important a time that sometimes you want to save it only for yourself, to savor it, and to experience it all alone—especially if it's your first time.

Ron Richards is a Career Consultant with Star Industries of Macon, Georgia. His duties include job development and job coaching.

The Declaration of Interdependence

BY NORMAN KUNC • SEPTEMBER 1995, VOLUME 21, ISSUE 9

Do not see my disability as the problem.	Recognize that the real problem confronting people with disabilities is social devaluation, prejudice, and oppression.
Do not try to fix me because I am not broken.	Support me so I can make my contribution to the community in my way.
Do not see me as your client because I am your fellow citizen.	See me as your neighbour who, in this time of flourishing urban isolation, is reminding you of how interdependent all of us are on each other.
Do not try to change me. You have no right.	Help me learn what I want to know.
Do not try to be a competent professional. You will invariably do harm to me.	Be a person who cares, who takes the time to listen, and does not take my struggle away from me by trying to make it all better.
Do not use "pedagogical approaches" on me. To abdicate personal responsibility for your actions behind theories and strategies is pure cowardice.	Be with me, and when we struggle with each other, let that be the impetus of self-reflection.
Do not try to control me. I have a right to my power as a person.	What you see as non-compliance and manipulation, is actually me being in conflict with you. Help me learn how to negotiate at times of conflict. This is assuming, of course, that you can do this for yourself at times of anger.
Do not teach me to be obedient, submissive, and polite. You do me no favour.	I need to feel entitled to say "No" if I am to protect myself.
Do not try to be my friend. I deserve more than that.	Get to know me. We may become friends.
Do not be charitable towards me. The last thing this world needs are more Shriners or another Jerry Lewis.	Be my ally as I fight against those who exploit me for their own gratification.
Do not help me, even if it does make you feel good.	Ask me if I need your help. Respect my "No" or let me show you how you can best assist me.
Do not admire me. A desire to live a full life does not warrant adoration.	Respect me because respect presumes equity.
Do not tell, teach, and lead.	Listen, Support, and Follow.

This article has been updated and re-titled "A Credo for Support," © 1995 Norman Kunc and Emma Van der Klift.

ON THE 40TH ANNIVERSARY OF *Brown v. Board of Education:*

FOOTNOTES FOR THE HISTORICALLY IMPAIRED

BY FRANK LASKI
JUNE 1994, VOLUME 20, ISSUE 6

On May 17, 1954 the U.S. Supreme Court in Brown v. Board of Education unanimously declared: "In the field of public education the doctrine of separate but equal has no place. Separate educational facilities are inherently unequal." That most important civil rights decision signaled the end of legal segregation not only on the basis of race, but on the basis of physical and mental disability.

From the time when Senator Hubert H. Humphrey first introduced amendments to the Civil Rights Act of 1964 in order "to end the segregation of millions of disabled Americans", to the recent enactment of the ADA, Congress has consistently regarded Brown as the controlling standard for eliminating disability segregation.

Today, 40 years after Brown and just four years into the ADA, those who defend segregation on the basis of disability deny the connection to Brown and would have us forget the historical legacy common to all varieties of segregation.

Oscar Cohen, writing in The New York Times and elsewhere, objects to the use of the term segregation in reference to handicapped-only schools. Segregation, he says, implies legally imposed isolation associated with enslavement of African Americans and, as such, is powerfully negative. In his view, separate schools for some are benign and contribute to the positive development of students, therefore we should refrain from associating these places with values antithetical to equal protection. Cohen fails to take into account that the purposeful unequal treatment of both persons with disabilities and persons of color has often—if not always— been clothed with benign purposes and protective interests.

Al Shanker also dislikes the connection between disability-based segregation and racial segregation. He says the analogy is faulty: excluding children on the basis of color is "quite different" from putting a disabled child in a separate class or excluding a child who will "derive little benefit." After all, Shanker says, unlike the class of children with disabilities, "African American children have the same range of abilities and needs as white children."

Apparently Shanker has yet to come to grips with the fact that in the cities where the AFT reigns, segregation of children with disabilities has also resulted in massive resegregation of African American and Latino children. In New York City, for example, over 80 percent of the students in segregated special education programs are African American and Latino students. For the students in New York, Philadelphia, Wilmington and elsewhere, separate is no more equal now than it was before Brown.

We need not engage in prolonged debate with those who deny our history and the common ground people with disabilities have with African Americans and other oppressed minorities. Charles Houston, Thurgood Marshall, and those who challenged racial segregation from the 30's through the 50's, as well as John W. Davis who defended separation of the races, all knew the power of Brown would not be limited to the schools or to race-based distinctions. In his argument in response to Marshall in the Supreme Court in Brown, Davis opened:

"I think if Marshall's construction of the Fourteenth Amendment should prevail here, there is no doubt in my mind that it would catch the Indian within its grasp just as much as the Negro. If it should prevail, I am unable to see why a state would have any further right to segregate its pupils on the ground of... mental capacity."

Davis was right and in due time the Congress and the Courts recognized it.

Later, when it came to apply the equal protection of the law to people with disabilities, U.S. Supreme Court Justice Thurgood Marshall acknowledged and found compelling the common historical legacy of segregation. Reviewing the extensive record of social segregation of persons with disabilities throughout the first half of this century, including "the categorical exclusion of children from public school", Justice Marshall concluded that a regime of state mandated segregation of persons with disabilities emerged that "in its virulence and bigotry rivaled and indeed paralleled the worst excesses of Jim Crow."

Shanker, Cohen and the rest may choose to ignore Justice Marshall and attempt to erase the historical record from the consciousness of their followers. However, because they have not paid attention to the history, they are too late to revise it. The Congress—both in IDEA and in ADA—acknowledged our history and persuaded that segregation on the basis of disability constitutes the same evil as racial segregation, and acted to eliminate it.

Forty years after Brown it is clear that for many African American children, ending segregation "with all due deliberate speed" meant no speed at all. The task of providing a remedy for children in grossly inferior, racially isolated schools remains to be accomplished. Similarly, for many children with disabilities, education with non-disabled children in regular education classes, "to the maximum extent appropriate" has meant no integration at all. Even the prospect of full inclusion has unleashed incredible attacks on children with disabilities and their families, with calls to repeal the protections in IDEA.

On this 40th anniversary, we need to do more than reflect upon the central importance of Brown to the civil rights of all people. We need to do more than rest our present efforts on the historical experience that brought us to Brown and from Brown to the ADA. We need to embrace today the same struggles and sacrifices that were necessary after Brown to overcome the massive resistance to ending separate schooling and extending equal protection to all citizens in all

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aspects of our national life.

Shortly after passage of ADA, Justin Dart wrote, "*Equality, prosperity and improvement have never been handed down to a disadvantaged people by an entrenched status quo... Real life improvement occurs only through consistent advocacy, action and vigilance of those who seek it.*"

Much earlier, Frederick Douglass made the same point, more bluntly, "Power concedes nothing without a demand. It never did, it never will."

> **". . . We are still facing brutal attacks and possible setbacks to the progress we have made over the course of my lifetime and those of many of you here. I must warn you that many of us believe these attacks will continue to get worse before we turn the tides again.**
>
> **Make no mistake about it: those who put this multiple attack strategy together are quite clever. They mean to divide and conquer us. What they are hoping to divide and conquer most is our time, our energy, and our focus. Every fight we are having to wage is important, in fact critical, to the very lives and futures of people with significant disabilities."**

— Commissioner Bob Williams
Administration on Developmental Disabilities,
Administration for Children and Families,
U.S. Department of Health and Human Services

TASH members, knowing the growing threat to inclusion, understand firsthand that Douglass, 150 years ago, and Dart today, speak to a constant historical truth. We know we must renew and intensify our advocacy for inclusion.

Update on BRI/JRC

BY NANCY WEISS

MAY 1996, VOLUME 22, ISSUE 5

Each of us, I think, has some issue that touches him or her most directly. Those of you who know me, know that the cause that has been most central for me over the past many years is the abolishment of the use of aversive procedures.

A number of years ago, I was asked by a state department of developmental disabilities to visit several individuals from their state who were housed at the Behavior Research Institute (BRI) in Providence, Rhode Island. These young people had been placed at BRI because the state had been unable to serve them but now, officials of the state department were anxious to bring these individuals back and provide appropriate supports for them. I was asked to assist the state to determine the kinds of supports these individuals would need to be successful in their own homes and communities.

I had heard about BRI for years, but nothing prepared me for the first hand experience.

I had heard about BRI for years, but nothing prepared me for the first hand experience. As I stood watching, one of the young men I had come to meet glanced up at me. "EYES ON WORK" shouted his instructor. The young man raised his arms, eyes blinking in a motion that was at once one of self-defense and surrender, as the instructor reached for one of the ever-accessible pressurized water hoses. The young man was sprayed in the face for several minutes until he was sputtering and his shirt was soaked. Then, with the helpless look of one resigned to the bleakness of his situation, he returned, dripping, to the task in front of him without so much as even pausing to wipe the water from his eyes.

Later that day I saw a young girl pulled from her work station and forced into a kneeling position. Her ankles were strapped down behind her and her wrists were strapped to a low bench in front of her. A helmet that BRI calls a visual screening helmet was placed over her head, covering her face and coming to the tops of her shoulders. The helmet blocks any light and emits loud white noise in the wearer's ears. In addition, a pressurized water hose is attached to the front of the helmet, rhythmically spraying the wearer's face with bursts of water. Children were forced to wear the visual screening helmet for a minimum of fifteen minutes or up to a half hour if they struggled or made noises. Although I had been standing right there, I could not discern what offense had been committed leading to this young girl being forced into the visual screening helmet. When I asked I was told that she had made "unnecessary noises". It was common for BRI to use the visual screening helmet, electric shock, finger pinches, ammonia spray, hot pepper sauce to the mouth, and bare bottom spanks for

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UPDATE ON BRI/JRC

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behaviors as innocuous as taking one's eyes off work, getting out of one's seat or bed, blinking eyes rapidly, speaking in a high-pitched voice, repeating sentences others say, toe walking, leg shaking, etc.

I left my two days at BRI a changed person. I learned that five children or young adults had died at BRI either during or soon after being subjected to a range of painful procedures. I knew I personally had to do something to end this abuse but many had tried before me and I was unclear as to what I could do that would have any impact. What was clear to me was that the children and young adults held at BRI were no less political prisoners than were the people on whose behalf Amnesty International worked. Over the next year I researched the use of aversive procedures at BRI and at schools and residential settings across the country.

As part of this effort a disability advocate journalist and I arranged interviews with current and former employees of BRI. Below are some quotes from these interviews:

> *I've seen kids so badly beaten we'd have to switch cheeks, then move to the thighs, then calves, then the bottom of the feet ... nowhere where it would show.*

> *There are parents who abuse their kids but not eight hours a day. These kids don't graduate. It's day-in and day-out beatings - a constant barrage.*

> *It's against the policy to form relationships with students. We use taste aversive sprays in the mouth, a special kind of finger pinches, ammonia pellets, spatula spanks. We make our own helmet so you can adjust the shock level. It's stronger and the wires can go anywhere: the torso, fingers, hand, bottom of the foot, inner thigh ... not on the genitals or on the chest or on the spine. It might give them a heart attack or paralyze their spines.*

TASH unequivocally opposes the use of aversive techniques such as those used at the Judge Rotenberg Center.

> *We have a student who wets himself. (The director) wants to sit him in a room and shock him while he's urinating or defecating, naked.*

> *When I worked there they would do mechanical restraints, in a booth, spray water, restrained by ankles and wrists. Water would splash out through this helmet. There was a button the kids could stop it with, but the kids didn't know how. They just put that button in for show. To show the kids could stop it if they were drowning or something but really, none of the kids knew that the button was there.*

> *You wouldn't go for it if you'd seen what was done for different behaviors. . . how could they live with themselves? How could they close their eyes and sleep knowing what was a going on?*

Based on my research and these interviews, I wrote a paper detailing the use of aversive procedures and sent it as a call to action to Amnesty International, urging them to add this abuse of human rights to their mandate. Amnesty International showed little interest in the issue. Sometime later, I contacted CBS and a news magazine show segment was filmed that included footage taken by a staff persons using a hidden camera. I felt certain that if the inhumane conditions at BRI were brought to light, public outcry would assure that such outright abuse could not continue.

This certainty was unfounded. All of this happened years ago. My visit to BRI was in 1989. The news magazine show aired in 1994. BRI has changed its name to the Judge Rotenberg Center (JRC) but little else has changed.

In February, 1995, Massachusetts lawmakers heard testimony for and against BRI's continued use of electric shock and other aversive procedures. Under questioning, Dr. Matthew Israel, BRI/JRC's Executive Director, conceded that one student received 5,300 electric shocks in one day. In March, the Massachusetts State Department of Mental Retardation (DMR), with the approval of Massachusetts' Governor and Attorney General, ordered BRI/JRC to stop all use of electric shock but BRI/JRC attorneys obtained a court injunction preventing the State from decertifying the school and the abuse continued. In October, 1995, a Probate Court judge ordered that a receiver oversee BRI/JRC, stripping the Department of Mental Retardation of its oversight duties.

At that time, I wrote on behalf of TASH to Governor Weld of Massachusetts in support of Commissioner Campbell and the State's right to protect the rights and safety of the residents of the Judge Rotenberg Center. Our letter stated:

> *TASH unequivocally opposes the use of aversive techniques such as those used at the Judge Rotenberg Center. Abuses in the name of treatment are imposed upon people who are less able to speak out against mistreatment. These abuses would not be tolerated if used against people who are elderly, the homeless, prisoners or even animals. Without using such techniques, people throughout the country are successfully supporting individuals with disabilities whose problem behaviors are as severe as those of the people residing at the Judge Rotenberg Center. We fool ourselves if we are to be convinced that the use of painful procedures is a necessary or conscionable part of treatment.*

Positive Behavioral Support With Families

JOSEPH M. LUCYSHYN,
ROBERT H. HORNER, & KATHY R. BEN

JULY 1996, VOLUME 22, ISSUE 6

This article describes the features of a **positive behavioral support approach** with families of children with **severe disabilities** and **problem behaviors** such as aggression, self-injury, and property destruction. **The approach** has been informed and shaped by families, professionals, and researchers as we have **developed behavioral support for children** in home, school, and community settings (Kern Koegel, Koegel, & Dunlap, 1996). For families, the **goals** of the approach are to **improve** the child's behavior and life-style, to **build** the capacity of family members to **successfully** raise the child, and to **strengthen** the family as a whole (Lucyshyn & Albin, 1993).

Positive behavioral support builds on a long history of behavioral research, but is guided by human values and the real life problems confronting families and teachers. The approach marries values with a technology of behavior change. The approach is both child- and family-centered. It is concerned not only with problem behaviors but also with the strengths and life-style of the child. The family is regarded as the child's "most powerful, valuable, and durable resource" (Dunlap & Robbins, 1991, p 188). The approach also is compatible with the inclusion of children with disabilities in typical school settings. Positive behavioral support offers practical solutions to the challenge of raising a child with disabilities at home and educating the child in his or her neighborhood school. Nine features, summarized below, characterize positive behavioral support.

1. A focus on life-style changes.

A child with severe disabilities often develops problem behaviors in the context of a life-style with limited activities and friendships. For this reason, a central aim of the approach is to create a rich and valued life-style for the child that is acceptable and feasible to the family (Risley, 1996). Life-style goals may include, for example, ensuring that the child participates each week in a variety of preferred home and community routines (e.g., eating dinner with the family, going on a walk with dad), and helping the child develop friendships with a relative or a neighborhood peer.

2. Building effective environments.

In essence, positive behavioral support is about building effective environments. The focus is not on changing the child with problem behaviors but on changing the features of home, school, and community settings. A good support plan defines changes in the behavior of family members and educators (e.g., teacher, language specialist, behavior consultant), and it is these changes in our behavior that result in change in the behavior of the child. Effective environments make problem behaviors irrelevant, inefficient, and ineffective.

3. Functional assessment: Understanding the purpose of problem behaviors.

A large body of research indicates that problem behaviors serve functions (Carr et al., 1994). For example, running away from a parent may provide a child with negative but interesting attention. Hitting a parent may terminate a demand to brush one's teeth. Functional assessment is a way to understand the meaning of problem behaviors from the child's point of view. An effective functional assessment includes interviews with family members and school personnel, and observations in the home or school to confirm emerging hypotheses about the purpose of problem behaviors (O'Neill, Horner, Albin, Storey, & Sprague, 1990). The outcomes of a functional assessment include: (a) a description of problem behaviors; (b) a list of conditions or events that predict the occurrence of problem behaviors; (c) clear hypotheses about the purposes of problem behaviors, and (d) direct observation data. The goal of the process is to use the assessment information to design an effective support plan.

4. Recognizing that problem behaviors are problems of learning.

Children with severe disabilities often develop problem behaviors for two common reasons. First, they may not possess the behaviors or skills that would take the place of problem behaviors as a means for achieving their wants or needs. For example, a child with autism may scream loudly while alone in the family room whenever she wants a new Disney video placed in the video machine. She screams to get an activity because she doesn't have the language skills to ask for help, or the performance skills necessary to change the video herself.

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Second, the social environment of the child may inadvertently teach the child to engage in problem behaviors. By our response to problem behaviors, the child may learn that the behaviors "work." For example, the parents of the child may respond to her screams by entering the family room and changing the video for her. The central message here is that problem behaviors can be reduced by teaching a child new behaviors and skills that make problem behaviors irrelevant to achieving his or her wants and needs.

5. Seeing communication as the foundation for positive behavior.

Many problem behaviors occur because the child does not know a more appropriate way to communicate a want or need. Understanding the purpose of problem behaviors is an essential first step for identifying the language (verbal, gestural, or augmentative) the child needs to communicate (Reichle & Wacker, 1993). For example, a child with a developmental disability may hit his head on the floor to get his mother's attention. He may be taught to communicate his desire for attention by saying or signing, "mom!" or "I need help." If the mother is his primary source of attention, then it also would be necessary to increase the number and quality of social events with other family members and peers, and to teach the child to request attention from these individuals as well. Teaching language skills is at the heart of any effective behavioral support plan. An effective support plan ensures that using language is more effective and efficient at achieving one's wants and needs than engaging in problem behaviors.

6. Designing multicomponent behavior support plans.

An effective positive behavioral support plan typically includes multiple components (Horner & Carr, 1996). Five categories of intervention are commonly present: Ecological or life-style interventions, preventative strategies, teaching new behaviors and skills, effective consequences, and emergency procedures to prevent injury.

A good support plan creates a rich pattern of activities and relationships, but avoids the features of situations that "trigger" problem behaviors. Consider a boy with autism and deafness transitioning from a day-care center to home. When his father asks him to walk to the car, the boy tantrums. He does so to avoid the transition. From the child's point of view the transition is aversive. It interrupts preferred activities at day-care (e.g., snack time, playing with a peer). Also, he cannot predict what will happen after leaving with his father. For each feature of the problem, the family and consultant can define a support plan component. For the absence of predictability, they design a picture schedule of steps in the transition routine. In place of the aversive demand to leave, the parents offer a choice of preferred events (e.g., a healthy treat, seeing the ducks at the park), and a positive contingency statement ("Let's walk to the car and then go to the park!").

An effective plan also includes consequences that make problem behaviors ineffective and inefficient at achieving their purpose. For example, a young girl with autism screams to avoid parental demands to perform tasks independently (e.g., using utensils to eat at the dinner table). The family introduces the following consequence. When the child screams, a parent immediately states a safety signal, "two more and then we rest," briskly puts the child through the task, and then gives the child a short break. Although screaming is not rendered entirely ineffective at escaping the task demand, it becomes very inefficient at achieving this purpose. After a few days, the child stops screaming and begins calmly (and later happily) using her utensils to eat. Effective consequences also may involve mild forms of punishment such as brief reprimands or a temporary loss of privileges, but never include procedures that cause physical pain, loss of dignity, or humiliation.

7. Designing contextually-appropriate support plans.

Another feature of positive behavioral support is the design of plans that are not only technically accurate but also a good "fit" with the characteristics and ecology of the child's family and home life, or the child's teacher and school (Albin, Lucyshyn, Horner, & Flannery, 1996). Designing a plan that possesses a good "contextual-fit" requires that we listen to and learn from family members and teachers about themselves and the settings in which they support the child. For families and home-based support, a good support plan should reflect family goals and values, build on family strengths, incorporate available resources and social supports, and diminish stressors.

Because of the complexities of family life, and the many demands on parent time and energy, we also have found it useful to implement behavior support plans in one valued family routine at a time (e.g., getting ready for school in the morning, going grocery shopping with a parent), and to embed support procedures into the ecology of routines (e.g., time, place, people, resources, tasks, goals). By doing so, plan implementation becomes focused and simplified. Family success in one routine builds confidence and momentum toward success in other

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routines. The central message here is that designing contextually-appropriate support plans may make the plan easier to implement and promote durable changes in behavior and life-style.

8. Developing collaborative partnerships.

Within a process of positive behavioral support, we strive to develop positive, reciprocal, collaborative partnerships with family members, educators, and other key stakeholders (Turnbull & Turnbull, 1991). We view family members as experts in their own right; experts about their child, about their family's culture and ecology, and about their goals and visions for the future. We recognize that for the holistic goals of positive behavioral support to be fulfilled, each of us must listen, learn, and change together. During assessment and plan design, for example, parents and other team members strongly influence the selection of interventions. During implementation support, parents and the child's teacher actively participate in evaluating progress and improving interventions.

9. Supporting with humility.

We believe that the complexities and subtleties of effective support to children with disabilities and their families require an abiding sense of humility. In our work with families, we do not find that we have all of the answers to the issues and problems confronting the child, his or her parents, or the teacher at school. During assessment activities, for example, family members and educators share their knowledge about effectively supporting the child, and these insights are incorporated into a proposed plan. Throughout implementation support, the consultant remains alert to errors in plan design, and responsive to critical comments from family members or educators about the acceptability or feasibility of plan procedures.

In summary, positive behavioral support is an approach to understanding why problem behaviors occur. The approach involves engineering effective environments in which problem behaviors are no longer functional (useful) from the child's point of view. Multicomponent support plans are designed to be effective and contextually-appropriate. During the support process, collaborative partnerships are forged with the family and other stakeholders. Through this unity of thought, action, and spirit (Singh, 1995), families are empowered to achieve their vision of family life in the home and community with their child with disability.

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Families interested in receiving more information about positive behavioral support are encouraged to contact the Family Connection, a national referral service, at (800) 854-4938.

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Take Risks, Ride the River

BY BARBARA BUSWELL

VOLUME 18, ISSUE 5

Last June our family took a river trip to Utah for seven days. Since we live in the West, taking a river trip isn't a very exceptional experience because a lot of families in the West take rafting trips. But there were a few exceptional parts to our trip. The most unusual part was that there were three grown-ups and nine teenagers on this trip.

We planned this trip ourselves since my husband, Mark, is quite experienced at rafting. As with all trips this adventure was a lot of work. One of the very first challenges of the trip was orchestrating the teenagers and getting them up in the morning! After we awakened the kids, cooking for 14 people was quite a challenge. The next challenge was to pack everything that we had used and load the rafts again so we could set out for the day.

The first day we had planned to leave at 9:00, and we got on the river at 1:00 because orchestrating the kids proved to be a much greater challenge than we ever imagined. As we set out down the river, we proceeded in a caravan with our four rafts and two kayaks. We enjoyed the sun, had water fights, battled the wind, supported the kids with interactions when they got too tired to paddle and when they were tired of sitting in the same raft with each other.

At day's end, we dragged everything off the rafts and set up for dinner. We learned to prepare all kinds of delicacies. We learned to do bathing and hygiene in the wilderness, escape from the bugs, deal with sunburn and also found some way to be away from the group and find a little peace. The kids really enjoyed the evening and explored the canyon, found snakes and even created some plays in which they acted. After dinner was a time to sit around the fire, have some time to reflect, get away from people, build sandcastles, talk and dream about the good life. As you can imagine, the adults savored the evenings after the busy days.

On the last day of our trip, we had a particularly notable experience. As we began to unpack, several other rafts floated up to the take-out point as well. The kids called to me that amazingly there was another raft on the river with a person who used a wheelchair. We soon noticed that actually there were three rafts who had people with disabilities. This was a "special" raft trip.

As we unpacked, a leader from the other group came over and said "Oh, you guys do trips for people with disabilities too." And I said "No, this is a family trip." We talked for a bit as I unpacked, and she asked me a number of questions. The first question was how long we had been on the river. I said "We have been on seven days." And she said they had clients with very severe needs and their clients couldn't tolerate such a long trip so they were only able to take a four-hour trip. She asked me how we fed our son on the river, because she said that eating and preparing food was very hard for their clients and she didn't know how we would be able to accomplish this. I told her, "We used Wilson's gastrostomy tube and washed his syringes with all the other dishes using boiled river water with a little Clorox." She asked how we arranged for sleeping. They didn't spend the night on the river since some of their clients used wheelchairs and wouldn't be able to get in and out of tents easily. I told her "Two of us, whoever was available, lifted Wilson in and out of the tent in whatever fashion people could get him in and out." She asked who was on this trip to support our son since their clients required at least one adult per client to meet their intensive needs. I said "We all supported him. His dad and I did most of the feeding and gave him medicine, but the other kids did most of his other physical assistance supports during the day." Then came the topic of heat stroke and heat exhaustion. She asked how we kept Wilson from wilting. "Well, we all wilted a lot," I said. With the squirt guns, swimming, water fights and tossing Wilson in the river when he told us when he was hot, heat stroke hadn't proved to be a problem. What about physical therapy while we were on the river? Clients with physical disabilities need therapy to keep their bodies working. I replied, "Well, we had no physical therapy for a whole week, but we had swimming, floating with a life jacket, stretching out on a hot tube of the raft, bumping through the rapids on a big cousin's lap and, if you weren't too sunburned, you might get a lotion massage in the evening." The woman ended the conversation saying that she admired us and was glad that our son had the ability to participate with us on this trip.

The leaders of this special trip seemed like good people, trying to do good things for people with disabilities. But somehow this context was wrong. Interestingly, later in the evening as we were driving away toward civilization waiting for a hot shower, my niece said to me that she thought it was very strange that this group of people had so many

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individuals who could walk, talk and do things that Wilson isn't able to do, but they looked so handicapped. And she said "I think it's because there were too many grown-ups hovering around the people."

The points from this river trip story are simple. Wilson wasn't a client on our trip, he was another kid, a member of the family, one of the cousins on this trip. We didn't have any adult support staff assigned. Wilson didn't need it, though—I did! Wilson's needs took a little extra thought and a little extra work, just like home. But in the vast logistical process of living in the wilderness for seven days with all of these kids, assisting Wilson required only tiny extra steps. Besides, we had his food grinder to create guacamole and humus, and loaded his wheelchair to carry gear every day.

The big deal about our trip was the attitude and questions of some other people, often professionals. When some people learned about our planned trip, they got real quiet and asked us serious questions like, "Why would you take Wilson on this trip?" "Don't you guys need to get away?" "Wouldn't it be too dangerous?" "What if he has a seizure?"

Now in case anybody is whispering—"they're an exceptional family"—I want you to know that we are not. We are just an average family. Our family happened to have the rafting skills to do this trip, but that wasn't the point. The river trip is parallel to many other situations in our lives and the river trip is a metaphor for Wilson being a part of whatever action is going on— whether it's being a counselor-in-training at summer camp, adapting a bike so he can ride with his classmates, or volunteering at the soup kitchen. Those are the action spots where Wilson wants to be. We don't want programs or models or systems or special trips. Instead we would like to be offered support for things we need in our natural environments.

Navigating the river was much, much easier for us than navigating the school system that asks frequently why kids like our son should be in regular education all day. Don't we understand that he has intensive needs; that his needs are too great to be served in a school with no other kids with disabilities; that the specialists aren't there. Don't we understand that the school can't really do this or that? Don't we understand because he has a disability, he probably should be out in the community and not in the classroom?

Well, it's just like pureeing dinner on the river. Wilson needs to be where the action is, and we can offer the supports there. People with disabilities don't need spray bottles to keep them cool; they need squirt guns; they need action; they need fun and they need cousins and friends. Kids with disabilities need to sleep on lumpy ground in a tent, even if their cousins dragging them through the door give them a bumpy ride. Wilson deserves to experience the challenge and stress of the river trip just like the rest of us. Surprisingly—or maybe not—on the trip everybody but Wilson became frustrated and blew their cool at least one time. But Wilson, in spite of the intense heat, having to be strapped into one position for long periods of time, being scraped and chaffed from the life jacket, and not being able to get those bugs away from his mouth, didn't lose his emotional composure. Wilson certainly deserves to ride through the rapids, feel the rush of the icy water in his face, and also celebrate the triumphs with his brother and sister and cousins.

So how does all of this relate to TASH? As TASH members, I am asking that we all work together to build a country where people stop asking why and start asking "how." The system of support and services that we create must come to the individual and offer choices, resources, suggestions and opportunities so that everybody can have rich lives filled with as much adventure as they choose. No one should ever tell our family, or any other family, or any person with a disability that somebody can't do something because of his or her disability.

As a new Board member, I have been thinking a lot about what this important organization can do for people. TASH is much more than an exciting yearly conference. It's much more than the JASH *Journal* that has articles that has helped us many times get the things we want. It's much more than the *Newsletter*, the committees, the executive board, the staff, the important resolutions, the governmental affairs presence and the other things we do. TASH is also a values-driven bank of individuals who, I hope, actively live out the mission and make a difference day-to-day in people's lives.

This means that being a TASH member isn't necessarily easy or comfortable, just like being on a river trip isn't always easy or comfortable. It may well mean the opposite is true. Sticking up for what we believe is often hard work. It's risky because the system wants us to stay in the boundaries of current reality. However, realizing the mission of TASH means pulling together and focusing on the important issues. It means breaking the trail, standing up for what's right, and walking beside each other as we work to make change. It probably means inconvenience, pressure, stress and political challenges at work, but being a TASH member, I hope, means acting congruently with our values. It means walking our talk and doing what's right.

A final note, that I can't emphasize enough, is the urgency of these issues. I feel incredible dissonance when I learn about new things that could work very effectively for our son, but face resistance with the people in the trenches. When day after day I am asked to wait until the teacher becomes comfortable, or the therapist learns a new approach, or the administrator understands his or her responsibilities with inclusion, or the school board finds enough money to put an elevator into a building, I am incredibly impatient. Each day that happens, Nelson loses time and misses opportunities. Missed opportunities are a tragedy. All Mark and I can give our kids, all three of them, is a history of living a quality life filled with family, friends, learning, adventure and rich participation in everything around them. Every child and every adult deserves these same opportunities for a good life. A life where everyday counts.

And so, I ask for your hand and your help. Use the intensity and urgency that children, parents, and adults with disabilities present to all of us. Focus on good lives; follow what's right. Go around or go through or go over the political constraints that appear constantly. Don't look away, and please don't ask us to wait. TASH is committed to stretching the boundaries for what is possible. So I ask you to take risks, ride the river and build opportunities for children and families and adults with disabilities.

No Time for Silence

BY DOUGLAS BIKLEN

DECEMBER 1996, VOLUME 22, ISSUE 12

In recent years, TASH has reached out to support self-advocacy and self-determination. This is reflected in TASH conference keynote addresses by people with disabilities — Sandra Jensen's address this year— in the participation of self advocates in the conference and on the Board, in the home-of-your-own coalition, and in collaboration with ADAPT and other disability rights groups. It is also reflected in TASH's commitment to pursuing science that makes a difference in people's lives by supporting self-determination and inclusion.

The issue of facilitated communication has often been cast as a scientific issue: i.e. is it real or not? It is also a political issue: i.e., what kind of research should we do and to what end; should we support facilitated communication users and, if so, how; and what responsibility do schools and agencies have for allowing and supporting facilitation? This article suggests that TASH members cannot support a self determination agenda by remaining silent on the facilitated communication controversy. As with every other issue we address, a commitment to science, self determination and inclusion can and must go hand-in-hand.

Whose Side Are We On?

Lucy Harrison has autism and until her early teens was assumed to be moderately retarded and unable to read. In 1989 she began to learn to express herself using facilitated communication. Since then, she has appeared on two television programs (including ABC Primetime Live and NBC NOW) and has been written about in the New York Times Magazine. Currently, she takes college preparatory high school courses in English Literature, Mathematics, Science, and History, and has plans to attend college next year.

Two months ago, Lucy Harrison gave a presentation at a conference on autism sponsored by the Geneva Centre in Ontario, Canada. She spoke her speech — recently she has been able to read aloud what she types with facilitation. She still cannot speak conversationally in sentences, but she can read her own prepared text.

Despite her successes, she recognizes and worries about the controversy surrounding facilitated communication. The world may appreciate the controversy, seeing it as a kind of contest, but she wonders at what cost. "Will voices be silenced forever? This is the fear that haunts me." "Perhaps one day," she writes, "I will look ... and see really free people. But today there is thick confusion, too much pain, and trash of dreams."

It seems to me that the question facing TASH members and other people in the field is where to locate ourselves in the debate. Unfortunately, the debate usually boils down to whether the method is real or not, legitimate or hoax, a way of eliciting words of people with communication impairments or words of their facilitators. This way of framing the issues clouds real understanding.

We already know that in some studies all of the facilitated communication users were unable to prove they were authors of the words typed with facilitation. Yet we also know that in some studies the majority of those tested *were* able to prove they were typing their own words. Predictably, researchers will continue to explore the issue of authorship as well as many other questions about the method.

But as Lucy Harrison explains in her writing, this is more than an academic debate. It is a struggle over whether certain people will have any voice at all and whether the world will hear them:

The battle will continue and there will be many casualties. There will be people who will reach the end of their lives without having a chance to talk to the family and without a chance to show who they are inside. I hope that there is a heaven where at last they will be free.

Action Steps for A Change:

The last seven years of research and experience with facilitated communication provide a solid basis for formulating a progressive agenda on facilitated communication. The following are action steps that TASH members can take to support people who use facilitated communication or who might benefit from learning to communicate with facilitation (please note that these apply not only to facilitated communication but to any situation involving people whose communication has historically been disregarded or suppressed).

1. Know what the method is and what it is not. Facilitated communication is a means of communicating through pointing, with physical and emotional support from a communication partner. It may be useful for people who cannot speak or whose speech is limited and who cannot point reliably. Facilitated communication is *not* a cure for autism. It does not work for everyone. It does not guarantee high level communication for all who use it.

2. Support the right of people to communicate and to prove they are communicating. The TASH Resolution on Facilitated Communication supports the right of individuals to have access to any method that might help them, the right to speak freely, and the right to prove that they are communicating their own thoughts. Whenever educators try any method, they cannot be sure whether it will succeed with a given individual. But one thing is certain about facilitated communication and every other method, if you do not try it, it cannot work. And you will never know if it might have worked.

3. Support people to use the method in everyday settings; this means making sure that schools provide equipment, facilitators, appropriate training, and assistance to families so that they can learn about the method. In 1994, Sharisa Kochmeister addressed the TASH conference through typing; she is a person who at one time had a measured intelligence score of 10. She does not speak.

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She learned to communicate first through facilitated communication and now types without physical support; her father, step mother, and sister need only sit nearby for emotional support. Sharisa accomplished this level of independence after several years of using the method and with extensive support from family, school, and other interested friends.

At the 1996 conference of the Autism Society of America, Lucy Blachman typed without physical support. Yet she needed to have her mother sitting nearby. Since 1989 when I first met her in Australia, she has earned a Bachelors degree at Deakin University and is currently enrolled in a Masters Degree program at Melbourne University.

When I first observed her at her high school in Victoria, she needed arm support from her teaching assistant/facilitator. And under some conditions, particularly with a brand new facilitator, any communication at all was problematic. Yet even then, in 1989, I observed that with her mother's or Rosemary Crossley's hand resting on her shoulder, she could type out conversational text.

Lucy Blachman, Sharisa Kochmeister, and Lucy Harrison and many others have done well with facilitated communication. Each has attended regular classes, had the assistance of facilitators in school, had communication equipment available to them, had excellent training in facilitated communication, and had intense family support.

4. Be knowledgeable about the most controversial aspects of the method. Facilitated communication became especially controversial when fc users purportedly typed allegations of sexual abuse. Some of these allegations were found to be groundless. Others were found to be accurate. Recent law review articles (Dwyer, 1996; Phipps & Ells, 1995; Maurer, 1995; Luxton, 1995) and court decisions (Kansas v. Warden) have concluded that people who use facilitated communication must not be denied access to the courtroom just because they use an untraditional mode of communication; to deny them access to the courtroom would be a violation of the Americans with Disabilities Act and of the Due Process clause of the Bill of Rights. Simply put, individuals who make allegations must have a chance to prove that their words are their own. Then, courts will have to decide, as they must in cases involving speaking individuals, whether particular allegations are true or not.

5. Call for research that is sensitive to people's disabilities. In several studies, most of the individuals tested were successful in proving, under controlled conditions, that they were authors of the words they typed with facilitation (e.g. Cardinal, Hanson, & Wakeham, 1996; Sheehan & Matuozzi, 1996; and Weiss, Wagner, & Bauman, 1996). These studies appear to include disability-sensitive protocol conditions that are different from most studies in which all or most individuals being tested have failed. Such conditions include extensive practice, natural environments for testing, extended time for responding, involvement of the fc user in designing the study conditions, constant feedback and so forth. Such tests prove that it is possible to test facilitated communication, but that not any old test will do. Educators and parents need to advocate for test protocols that are disability-sensitive. Otherwise, we allow research to discriminate against the people being tested.

6. Support facilitated communication users to be in control of their own words. A major limitation of facilitated communication is that at least for some people it is easy to influence or cue their communication—of course it is important to recognize that all communication, including all augmentative communication, involves various kinds and degrees of cuing. And, in complex ways, all communication is co-constructed. This poses a significant problem in any communication situation where there is a real or potential imbalance of power among those involved; how do we ensure that people who use the method are supported to author their own words? Here are some suggestions:

- Be patient and try not to anticipate what a person is going to type; facilitated communication, like all augmentative systems, is much slower than speech and requires the communication partner to wait for what is being produced.
- Provide feedback. Let the person know what you are reading from their pointing and when you are not sure what the person is pointing at, say so, asking the person to point again. Also provide feedback and support in terms of how the person is typing; don't facilitate if the person looks away from the letter board, computer keyboard or other target — looking away leads to many errors in pointing and to reliance on the facilitator to guess what the fc user intended.
- Ask clarifying questions. There should be numerous situations in a conversation where you are not certain about what the fc user means. Ask for clarification: i.e. "I'm not sure what you mean? Could you explain that?"
- Encourage the fc user to feel comfortable making real choices.
- Encourage the fc user to state his or her own opinions freely and to disagree with you as much as he or she wants. If the fc user never disagrees with the facilitator, this is probably a good sign that the fc user is not taking control of his or her communication.
- Encourage the fc user to work toward and achieve independent typing for some or all of his or her communication. As Rosemary Crossley (1994) has explained, independent typing is a realistic goal for most fc users. But as we have found in our research, people who use facilitation are often not convinced they can achieve this goal or that it is even worth working on, unless they have a lot of support to do it.
- Encourage fc users to have many facilitators. This will maximize opportunities to communicate across multiple settings. Also, multiple facilitators will come to see that the individual who uses the method has a distinctive style, distinctive themes,

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and will share information across multiple facilitators; my colleagues and I discussed this in an article entitled "How Teachers Confirm Authorship of Facilitated Communication" which appeared in the Spring, 1995 issue of JASH.

7. ***Read the writings of authors who use the method.*** As individuals get good at using the method—some are achieving greater levels of independence and some develop extremely distinctive styles of composition— we have a new opportunity to learn about how a group of people with disabilities experiences disability. I especially recommend Birger Sellin's autobiography, recently translated from the German language: I Can't Live Inside Me Anymore (1994) and Sue Rubin's opinion editorials in the Los Angeles Times. These are provocative works, for they give insight into breakdowns in communication, problems with excessive stimulation in the environment, and the dangers of how mental retardation is currently assessed.

8. ***Don't be afraid to speak about the accomplishments of people who use facilitated communication.*** Sharisa Kochmeister now types without physical support. Sue Rubin and Lucy Harrison are planning to attend college. Jeff Powell has published some of his poetry. Birger Sellin's book offers valuable new insights into autism. We need to share this information with educators and communication specialists; these are important accomplishments that could give encouragement to thousands of others.

...not being able to speak is not the same as not having something to say.

9. ***Learn from people with disabilities about how the method works and how it best might be tested.*** Encourage thoughtful research on the method, especially research that honors the perspectives and advice of people with disabilities, including facilitated communication users. Donna Williams, author of Somebody Somewhere, Nobody Nowhere, and Like Color to the Blind, reminds us that unless we learn to listen to people with autism, we will not have a clue about how a person with autism experiences the world. Here is what she says in her 1994 JASH article about testing:

> ***The person with autism, in my view, learns quickly that the ways of people who do not have autism do not work for them. What is more, I feel they learn quickly that when they attempt to manage or sort out (and, inevitably react to and be frustrated by) their own systems' chaos, people without autism will generally treat their attempts as a 'problem' and will interfere like dentists working with garden tools who refuse to admit their way may not be the only comprehensible and right way of managing things and learning. One result for this may be that people with autism generally learn to 'smell out' the dentists who come along with garden tools and arrogant assumptions.***

Larry Bissonnette, an fc user who types with just hand-on-the-shoulder support, made a similar point when he wrote,

> ***You cannot learn titling of disability unless you imprint real experiences of people who live with limitations of lasting intensity on property of esteemed scientific inquiry.***

At the 1995 TASH Conference, Eugene Marcus gave a presentation on how he learned to do the name-the-picture style authorship test of facilitation first described by Wheeler and his colleagues at the O.D. HECK institution in New York State. Initially he found the test format very difficult, but with practice and several other minor modifications, he was able to use that protocol to prove he was communicating his own words. His research will appear in my forthcoming book (co-edited with Don Cardinal) entitled Contested Words, Contested Science: Unraveling the Facilitated Communication Controversy.

10. ***Presume competence, not incompetence.*** Current views of mental retardation still focus on deficits (i.e. what are the person's limitations?); it is time we began to challenge how mental retardation is assessed. The idea of presuming competence is an important rule for educators. It places the burden for success equally on the teacher as well as the learner. Any failure to elicit evidence of competence always begs for a new strategy or approach, a new way of finding ability. We have enough evidence from facilitated communication as well as from accounts of other augmentative communication aid users such as Christy Brown (My Left Foot), Ruth Sienkiewicz-Mercer (I Raise My Eyes to Say Yes), and Christopher Nolan (Under the Eye of the Clock) to know that had their parents or teachers not kept trying with them, they would never have succeeded to the degree they did. Each of them proves the point that not being able to speak is not the same as not having something to say. Historically, many individuals who today are recognized as being very capable were formerly kept silent and presumed retarded. And presumably many more are still silenced. It is time to abandon the deficit model and embrace the presumption of competence.

For an Annotated Bibliography of Selected Readings on Facilitated Communications, visit the Facilitated Communication Institute's home page: http://web.syr.edu/~thefci or write: Douglas Biklen, c/o Cultural Foundations of Education/Teaching & Leadership, Facilitated Communication Institute, School of Education, 370 Huntington Hall, Syracuse, New York 13244. The Institute can also be contacted by phone at (315) 443-2699.

IN MEMORIAM
A TRIBUTE TO ED ROBERTS

Ed Roberts made the news again on Tuesday, March 14th, but it was not as the outspoken disability radical who founded the Center for Independent Living, or the President of the World Institute on Disability that national press coverage centered. It was his death, from heart failure at home in Berkeley during the night, that once again brought Ed's incredible life story before the public eye, and reminded everyone what a tremendous force he was to the disability movement. A leader in every sense of the word, Ed Roberts kept the issues out in the open where you had to meet them face to face— "a quad with attitude" is how he jokingly described his effect on the establishment. He was also a valued friend and mentor to many at TASH, serving on the Executive Board from 1991 to 1994. With his son Lee, Ed had another role to fulfill—that of just plain Dad. As his presence was so keenly felt, his wide circle of friends will each feel his absence as strongly for a long time to come.

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Ed Roberts had an impact like few leaders, much less "disabled" leaders, and he will be missed throughout the world. He was one who could tame bureaucracy, speak to children and the high and mighty alike, and build from courage and possibility.

I'm sure he's mad as hell that he was taken down by a heart attack. He probably would have rather been run over by an inaccessible bus that he was chained to. We will miss him.

— Judith Snow

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We were doing a presentation to about a hundred students at the Auckland College of Education at the same time that Ed breathed the last breath of his life. As far as we can calculate, that would have been about the time we were showing the slides we have of Ed swimming with dolphins —even giving one of the dolphins a kiss. We use that sequence to make the point that nothing is impossible.

Ed was, is, and will continue as an inspiration to us and many more—and our tribute to him will remain unchanged. The sad part is that for many, they will be denied the opportunity to learn from Ed directly, but will have to learn from the stories of Ed's wisdom as he taught all of us.

We miss him, honor him, and will keep Ed's memory alive. The issues he dedicated his life to remain issues. This is not the time to stop, but rather be reenergized and recommitted to achieve those shared goals—for Ed, and for all of us.

— Jack Pearpoint and Marsha Forest

JUDY HEUMANN
ASSISTANT U.S. SECRETARY OF EDUCATION
SPEAKS TO TASH

I had a deep respect for TASH more than two decades ago, and my admiration for your organization has grown stronger over the years.

Twenty years ago, you were pioneers in the deinstitution-alization movement. Over the years, you were among the leaders in the struggle to insure that this nation adopted as a goal the opening of opportunities for every disabled man, woman, and child to lead full and fulfilling lives as integrated members of their communities. And today, you are still on the front lines. You are among the primary leaders in making sure that our public policy guarantees that every person with disabilities has the resources and supports they need to make their full contribution to American society.

American society is beginning to catch up with TASH. Decades ago, it was almost universally assumed in the United States that disabled persons could not live independent lives as working, contributing members of society. Too often, those with disabilities were considered objects of charity and hidden away. Today thanks to TASH and other progressive groups in the disability rights movement, the paradigm regarding disabled persons has changed. The Americans with Disabilities Act, the Individuals with Disabilities Education Act, and other laws, reaffirm that the right to equal protection guaranteed by the United States Constitution extend to people with disabilities. Today our laws state that disabled people should have — as a matter of right — full equality of opportunity and access to the same choices and opportunities as non-disabled persons.

I know that TASH must continue to play an aggressive part in the fight to protect the progress we have all made over the past 20 years. Your voices must be heard loud and clear in your local communities, the state capitals and Washington, D.C.

TASH NEWSLETTER

Priscilla Newton, Editor

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on language "that emphasizes the humanity of people with handicaps." Terms such as "the autistic," "the retarded," and "the severely handicapped" refer to characteristics, not individuals. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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( ) Higher Education
( ) Human Services Provider
( ) Interested Individual/Advocate
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( ) Parent/Family Member
( ) Primary Care Provider
( ) Personal Assistant
( ) Professional Advocate
( ) Psychologist
( ) Regular Education
( ) Residential Services
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Student (College/University)
( ) Support or Related Services
( ) Supported Employment Personnel
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( ) Teacher Trainer
( ) Vocational Services
( ) Other

General Membership (individual)	$85.
Agency/business/university/college/library/school (allows three conference attendees)	$190.
Self Advocate, Parent, Full Time Student, Direct Careworker/Paraprofessional/Personal Attendant (for whom payment of full fee would present a hardship)	$45.
Family (group rate)	$130.
Lifetime Member	$1000.

All dues are $15 higher for members outside the U.S. & Canada.

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How did you learn of TASH: ____________________

What, in particular, inspired you to join: ____________________

What other disability organizations do you belong to: ________

Referred by: ____________________

If you are applying for a student membership, please provide the following information:

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College/University ____________________

Student I.D. Number ____________________

Anticipated year of completion ____________________

( ) Please check here if you would like us to send information about your local TASH Chapter.

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MARCH 1997

Newsletter

EARLY CHILDHOOD

INSIDE:
Inclusive Early Childhood Programs, Child Care Inclusion, and Including Children with Disabilities in Head Start

DON'T HIDE FDR's DISABILITY

The FDR Memorial Commission spent $42 million dollars of taxpayer money and REFUSES TO SHOW FDR IN A WHEELCHAIR.

Rally in protest!

8 - 11 am, Friday, May 2, 1997
at the FDR Memorial
Ohio Drive, West Potomac Park

(This rally is taking place during the opening ceremonies of the FDR Memorial)

For information, call (202) 293-5960, TDD (202) 293-5968 or FAX (202) 293-7999
FDR in a Wheelchair Campaign, 910 16th Street. NW. Suite 600, Washington, DC 20006

BY FRANK LASKI

IDEA - Making It Work

We now have a consensus on IDEA and are about to see forged a 1997 consensus act. In an unprecedented show of personal commitment to an effective IDEA that could be fully funded ($10 billion), Senator Jeffords and Congressman Goodling called on all who care to participate in building a consensus for IDEA. That call from the chairman led to a remarkable series of Friday gatherings in the Capitol led by Trent Lott's Chief of Staff, David Hoppe. In the ornate, high-columned Senate hearing room, "plain" people – teachers, mothers, fathers, grandparents, and lots of students (some from nearby Fairfax, Virginia and others from as far as Honolulu, Hawaii) – told their individual stories, good and bad, heroic and sad. Senate staff and House staff listened intently over long hours and gave a reality check to previous proposals to improve IDEA.

From the six weeks of conversations in Washington, the 1997 consensus took shape. Parents and their organizations across the country testified that the fundamental protections in current law must be preserved so that:

- Parents can influence the education of their children (stay out);
- Children will not be excluded from education (zero-reject mandate); and
- Schools have and use promising educational practices that yield meaningful benefits to all students (state-of-the-art).

With the protection of current law intact, all stakeholders – parents, unions, school superintendents and school committees—can and will support full federal funding for IDEA, and support making Part B effective and enforceable through strengthening the professional development, research and other discretionary authorities.

The process initiated by the Congress this year has brought us light years from the bills of the last Congress. In place of bills no one could ever agree to, we now have on the surface a political bargain that will make a good IDEA. Now it is up to the Congress. The task is not to mediate, but to legislate in the honorable, bipartisan tradition of the 94th Congress that enacted the Education for All Handicapped Children Act and the 99th Congress that, in 1986, extended the earlier Act to the infants, toddlers, and preschoolers we celebrate in this *Newsletter*.

We can expect the best from this Congress. The leaders and their staffs have been attentive, and are attuned to how passionately parents care about schooling for their children. Make sure you let them know we all care.

Contact the following Congressional representatives to relay the message that Congress must:

Keep the Rights,
Realize the Promise.
MAKE IDEA WORK.

Senator Jim Jeffords
513 Senate Hart Office Building
Washington, D.C. 20515
E-mail: Vermont@jeffords.senate.gov
Fax: (202) 228-0338
Phone: (202) 224-5141

Representative Bill Goodling
2263 Rayburn House Office Building
Washington, D.C. 20515
Fax: (202) 226-1000
Phone: (202) 225-5836

Also, contact your state representatives!
Congressional Switchboard:
1-800-962-3524

REGULATING AVERSIVES: *Futility in Massachusetts*

On March 13, 1997 the Massachusetts Supreme Court upheld lower court rulings that the Massachusetts Department of Mental Retardation violated the terms of a 1986 settlement agreement with Behavior Research Institute (BRI) - now the Judge Rotenberg Center (JRC). The lower court found that the state agency impermissibly interfered with court-ordered treatment plans authorizing aversive therapies and engaged in bad faith regulation of BRI. The Supreme Court decision effectively brought to an end efforts by the state to monitor BRI. All regulatory and treatment decisions now reside in the Probate Court and that Court's appointed receiver.

Within a day of the Court decision, the Department of Mental Retardation Commissioner, Philip Campbell, resigned.

Since 1986, under an agreement with the State, BRI has used aversives such as electro-shock via "G.E.D." (Graduated Electronic Devices; equipment modified to graduate the level of shock intensity) devices and "Specialized Food Programs" (students do not receive food except that earned by meeting "behavior contracts"). The Supreme Court decision will allow BRI/JRC to continue its practices as long as states and their local agencies send students to the Massachusetts facility and pay for the aversive treatments.

The continuing controversies that have made BRI notorious have turned fairly straight forward issues concerning the basic human rights of children with disabilities, into high-cost legal and political disputes of Machiavellian complexity.

The fundamental policy choice made in Massachusetts to allow use of "Level Three" aversives, and then to regulate their use, preordained the result affirmed by the Court in the BRI case. Perhaps the Court's decision and its aftermath will focus us again to understand the inherent limitations of public bureaucracy to regulate closed institutions, or to protect people who cannot speak for themselves, from what may be inflicted on them in the name of treatment.

TASH has long called for absolute prohibition of the use of electro-shock in all its incarnation (Self-Injurious Behavior Inhibiting System (SIBIS), Graduated Electronic Devices (GED; equipment modified to graduate the level of shock intensity)). A legislative ban on all aversive procedures is overdue. Some states have done it (Connecticut). Massachusetts has a bill under consideration (H. 1910 An Act to Protect Disabled Persons). All states should know the lesson of BRI – Save its regulators and protect its citizens.

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TASH (The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services.

EDITOR'S NOTES

It's never too early to begin considering the educational options available for your child. Whether their first school-related experience is in day care, preschool, or kindergarten, parents are urged to begin planning early for their child's education.

This task is a major responsibility of any parent, especially for those whose children have historically been denied access to full and equal education opportunities. While Part B of IDEA guarantees the right to a free and appropriate education in the least restrictive setting for children with disabilities, many families must still battle to get educators, neighborhood schools, local communities, policy makers, and others to understand equal education is a right for all children - not a privilege for a select few.

Nowhere is it more critical to advocate the position of equal education for all children than in the area of public funding for schools. Several states, including Maryland, are considering (or have implemented) legislation that would allow the use of vouchers, purchased with public tax dollars, to fund private and sectarian education. Proponents of this action contend that vouchers will give parents greater choice and improve the quality of public education.

However, taking tax dollars out of the public school system under the guise of giving greater choice to parents and families will drain much-needed funds from already over burdened neighborhood public schools. Whether packaged as tuition tax credits, vouchers, or the current "education opportunity scholarships," we must be wary of the perilous implications such a program could have: public schools and their communities would be subjected to an outflow of tax dollars, students, and other resources to private schools - schools which set their own admission and academic policies and are purposely exclusive.

The search for ways to make public

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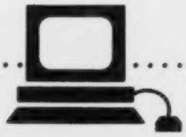

WHOM DO I CONTACT??

- **For issues of policy, chapter or committee support or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on the conference, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
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- **For information on the newsletter or to make a submission, call:** Priscilla Newton at (410) 828-TASH, Ext. 102.
- **Don't forget to visit TASH's web site at http://www.tash.org**
- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230, e-mail: lgoetz@sfsu.edu

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FROM THE EXECUTIVE DIRECTOR

BY NANCY WEISS

Parents of young children with disabilities face what may often look to be a series of insurmountable hurdles. Advocating, whether on behalf of your own son, daughter, or family member, or for people with disabilities on a broader scale, is a never-ending prospect. As soon as one goal is accomplished, another challenge looms around the corner. Even the shortest pause to admire our achievements, risks new limiting forces finding a footing and taking root. I am often asked what, in my view, will be the next biggest hurdles we will face as we continue the quest for communities, schools, and workplaces that challenge, engage, value, and include children and adults with disabilities.

Many of the toughest challenges for family members and other advocates will have to do with assuring quality supports as funding for all types of services is reduced. As resources become more scarce, family members and other advocates will have two options - to watch and wait, or to participate in the design and development of systems of quality supports for people with disabilities. Whether people in your state are using the term "managed care" or not, the same cost-saving principles are undoubtedly guiding planning. Though the trend toward reduced resources may be frightening, the fact that both on the national level, and in most states, a fresh look is being taken at service delivery systems, provides an opportunity for advocates to define the essential aspects of new approaches.

Often there is concern that "better" services will necessarily cost more. There is fear that any efforts toward creating higher quality support systems will be in direct opposition to cost containment efforts. All over the U.S., however, experience has shown that supports that are truly individualized and focus on including individuals in all types of currently existing settings are likely to cost less, on average, than do traditional, segregated services. The reason for this is that current systems have offered services clustered in ways that seemed expedient.

Imagine a child who needs help with receptive and expressive communication, or an adult who needs the support of another individual during the night and when he or she is traveling around the community - but not the rest of the time. In many communities that child would be in a segregated school placement and the adult would be placed in a group home where not only his/her specific needs would be met, but a whole range of other, less necessary, and perhaps even limiting supports would be provided as well. It is analogous to going to a restaurant that offers only a five-course, fixed-price dinner when what you really want (or need) is only soup or dessert. When the service system catches up to current thinking and allows people not only to choose from a broad menu, but to participate in the design of that menu, all individuals will be better served.

With the move toward managed care, advocates are offered an opportunity to participate in the re-thinking of the whole approach to community supports. In many states there has been movement toward bigger, more segregated, less individualized options. Clearly, if advocates do not doggedly pursue supports that are more responsive to the needs of families and individuals, we risk back-sliding. It is our continued challenge to find ways to assure that when systems are changed in response to limited resources, these changes are made in ways that will actively promote the full inclusion and participation of children and adults with disabilities in all aspects of life.

> **All over the U.S., experience has shown that supports that are truly individualized, and focus on including individuals in all types of currently existing settings, are likely to cost less, on average, than do traditional, segregated services.**

EDITOR'S NOTES

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schools stronger is everyone's responsibility. Only when we use our collective creativity, time, and financial resources to make our public institutions of learning the very best they can be, can we truly ensure a quality education for the benefit of all children, right from the start.

This issue of the *Newsletter* focuses on some promising new developments and revisions to programs and practices involving children at the infant through preschool stages. Grenot-Scheyer, Schwartz, and Meyer discuss inclusive early childhood programs and their impact on the educational experiences of young children (page 8), and the inclusion of children with disabilities in Head Start programs is highlighted in an article by Landau Fine, Grollman, and Howard, beginning on page 21.

Marcie Roth gives us an update on the progress of the Congressional Working Group on IDEA (page 11), and the Center on Human Policy relates the work of the Early Childhood Inclusion Network (page 14).

Look for information on the TASH Early Childhood Interest & Action Group (page 17) and a regular column beginning this month on TASH Chapter News and Views (page 20).

The 1997 TASH Awards application is located on pages 24-26. This year's application has been redesigned so it can be used for nominations for any of the TASH awards. And be sure to look for the conference registration form in the May *Newsletter*!

— Priscilla Newton, Editor

Making Connections

Making Connections is a column for and by the TASH readership. Do you have a particular area of interest that you'd like more information about? A desire to locate others who run programs similar to one your agency runs or is planning? Making Connections will be featured periodically in the Newsletter. You may want to hook up with others who:

- Have children with similar disabilities to your son or daughter
- Provide progressive community living supports
- Teach children who are similar to those in your class
- Know about resources for students with disabilities in college settings
- Have established inclusive summer camps
- Are using facilitated communication successfully
- Want to discuss the ethics of behavioral technologies
- Share your research interests
- etc., etc.

■ ...I'm Molly's mom. She had Rett Syndrome and died unexpectedly last April, when she was 17. I have been a strong advocate for inclusion both in Minnesota where we lived from 1985-1989, (Molly was the Tessar in _Tessar v. Mounds View_) and in Madison, Wisconsin where we've lived since 1989. I feel like I've spent too much of my adult life in the principal's office.

What I have found, even in "progressive" Madison is that inclusion can be quite elusive. Molly attended only regular classes basically because that was what I insisted on. At the high school she attended, there is still a group of homogeneously grouped students with "severe" disabilities, most of whom live at a nearby state hospital. These students spend their days in a self-contained classroom or being wheeled around the mall in what I call the "shop 'til you drop" curriculum.

When they are in the cafeteria, they all sit at one table. The "program" hasn't changed in 15 years. Had I done nothing, that's where Molly would have ended up.

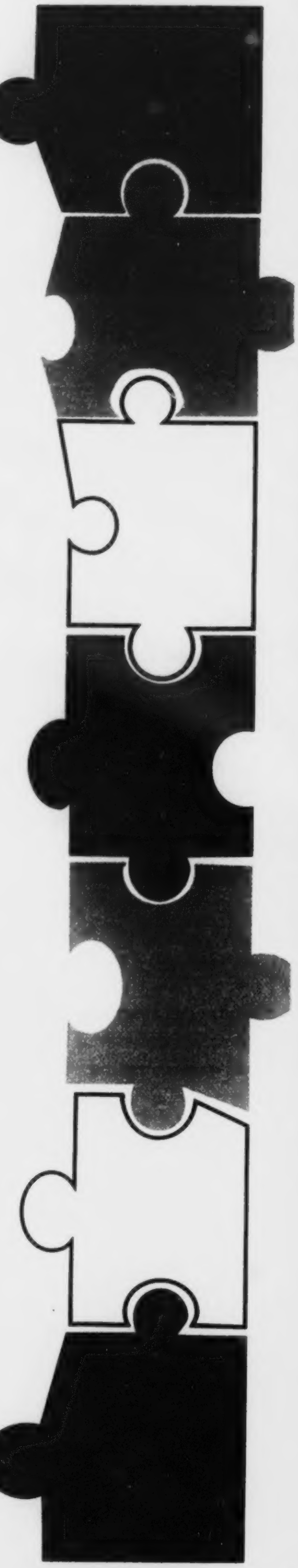
Yes, the people at the University seem willing to provide resources: student teachers, etc. But our high school isn't even ready for that.

What I am trying to get across is I would like the TASH membership, which I perceive to consist of a large number of professionals without children with significant disabilities to take a look at where they live. I'd like them to ask themselves what the schools their children attend look like. How inclusive are they? I'd like to see them start making changes in their owns schools, not as professionals, but as citizens, taxpayers, and community members.

Debbie Tessar
Madison, Wisconsin

* * * * * *

If You Would Like To Place A Free Announcement On This Page, Send it to: Attn. Dan Dotson, TASH, 29 W. Susquehanna Ave., Suite 210, Baltimore, MD 21204. OR e-mail it to: ddotson@tash.org OR Fax it, attention Dan Dotson: (410) 828-6706.



EQUITY & EXCELLENCE CONFERENCE ANNOUNCEMENT

October 1, 2, & 3, 1997

Portsmouth, New Hampshire

This conference is designed to broaden conversations about curriculum and instruction, school climate, standards-based reform, social justice, and sustainable change to include all students. Together, **with your school team**, attend intensive topical strands related to restructuring and inclusion, and network with colleagues to learn more about how schools can embody both equity and excellence.

Keynote Presentations:

Alfie Kohn • Norman Kunc • Bob Mackin

Strands:

Curriculum and Instruction • Student Empowerment and Social Justice • Roles of General and Special Education Personnel • Student Motivation, Conduct, and School Climate • Strategic Process for Changing to a Fully Inclusive School • Alternatives to Functional Skill Instruction • Standards, Assessment, and Grading

Host: The Institute on Disability/UAP, University of New Hampshire

Co-Sponsors:

Inclusion Press International • Center for Professional Educational Partnerships • NH Department of Education • Institute on Emotional Disabilities, Keene State College • Consortium on Inclusive Schooling Practices • PEAK Parent Center • TASH

For information contact Jean Clarke tel: (603) 228-2084 or email: jmclarke@hopper.unh.edu

Blending Best Practices for Young Children: Inclusive Early Childhood Programs

Marquita Grenot-Scheyer
California State University, Long Beach

Ilene S. Schwartz — University of Washington

Luanna H. Meyer — Syracuse University

The Consortium for Collaborative Research on Social Relationships: Inclusive Schools & Communities for Children & Youth with Diverse Abilities

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BLENDING BEST PRACTICES FOR YOUNG CHILDREN:

Inclusive Early Childhood Programs

Three traditions have had a significant positive impact upon the educational experiences of young children.

First, early childhood special education (ECSE) guarantees children with disabilities and their families individualized programs based upon assessed needs, and has long emphasized the value of preschool programs that enable children to interact with their typical peers.

Second, the Developmentally Appropriate Practices (DAP) guidelines for ages birth through eight developed by the National Association for the Education of Young Children (NAEYC) (Bredekamp & Copple, 1997) were developed in contrast to preschool and kindergarten curricula that stressed academics and cognitive development through more structured activities and focus on play, exploration, and child-directed activities. The DAP guidelines use the dimensions of age-appropriateness and individual needs as the basis for assessment, designing learning environments, and selecting teaching strategies throughout the early childhood years.

Third, early childhood programs must also incorporate the principles and practices of multicultural education. Multicultural education requires that educators transmit the concept of "cultural pluralism" (the state of equal co-existence among people from different cultural and ethnic backgrounds) into the daily life and routine of schools. "Culturally inclusive" programs must be designed to blend the principles and practices of inclusion, special education, and multicultural education (Harry et al., 1994).

We think that these three traditions — ECSE, early childhood education, and multicultural education — can be blended to support and nurture young children and their families in Inclusive Early Childhood Programs. We will present a brief overview of quality indicators of Inclusive Early Childhood Programs that blend these traditions and

continued on page 9

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BLENDING BEST PRACTICES FOR YOUNG CHILDREN

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illustrate what this blending looks like for one young child.

Indicator #1: Holistic view of child development

Teachers must enter the classroom with a thorough understanding of child development to support the inclusion of diverse learners. These teachers consider all domains of development as important and interrelated, and view development through the cultural and social lenses of their children and families. A holistic view identifies every child as unique and does not invite comparison of the behavior of groups of children—rather, it views each child's development profile as an individualized portrait of competence and areas in which a child may need additional support. This view allows teachers to identify, celebrate, and build upon the competence of every child.

Indicator #2: Class as Community

Educators can provide students with opportunities to enhance feelings of self-worth, social responsibility, and belonging—experiences necessary for developing compassionate citizens in a caring school community (Grenot-Scheyer et al., 1994). By assisting children with and without significant disabilities to feel that they are valued members of the school community, educators can be more effective in fostering development in all critical curricular areas. Schaps and Solomon (1990) stressed that promoting prosocial development is central to the creation of a caring school. Schools and classrooms can be structured to facilitate kindness, consideration, empathy, concern, and support for others. Such caring is critical in contemporary elementary schools as students are increasingly called upon to develop the skills needed to learn, play, live, and work with people who are different on a variety of personal and social dimensions (Nevin, 1993).

Indicator #3: Collaboration

Collaboration among personnel is critical to the success of children (and adults) in inclusive early childhood classrooms. Critical to the success of collaboration is that colleagues view each other as equals. They must share a common body of knowledge and repertoire of skills. Specific organizational structures must be in place to provide sufficient involvement to facilitate ownership. Frequent face-to-face interaction, positive interdependence, small group social skills, and clear individual accountability are all essential strategies. Collegial problem solving must be valued and not viewed as a last ditch effort. Proactive teaming will best support diverse learners in inclusive classrooms.

Indicator #4: Authentic Assessment

Assessment is an ongoing process used to evaluate student process and teaching strategies, as well as to form the basis for learning goals and objectives. While early childhood educators have a variety of assessment tools and strategies available to them, caution must be taken when using standardized measures with diverse learners. Authentic assessment strategies provide a more descriptive and meaningful approach to evaluation. Authentic assessment procedures consist of a variety of performance based assessments that require children to demonstrate a response in real-life context (Herman, Aschbacher, & Winter, 1992).

Indicator #5: Heterogeneous Grouping

All children should have opportunities throughout the day to work and play in diverse and heterogeneous groups that are responsive to individual strengths and needs. Group selections can be both teacher and child determined depending upon activity. Within a cooperative goal structure, children can engage in and learn from one another in various roles (Johnson, Johnson, & Holubec, 1986).

Indicator #6: Range of Individualized Supports and Services

Successful inclusion is dependent upon the belief that all children can learn, participate in, and benefit from all areas of the curriculum. This belief shifts the focus of individualized interventions from teaching prerequisite behaviors to providing appropriate support and modifications for participation and learning. Rather than providing "special" services outside the typical classroom, teachers and therapists work within the context of ongoing activities to provide the needed amount of support to facilitate participation, interdependence, and the child's acquisition of individualized goals. The range of support services and their intensity will vary across children and classrooms depending upon services already available in each room.

Indicator #7: Engagement and Active Learning

Active engagement is a concept derived from classic child development theories that emphasize the importance of learning by doing in meaningful contexts (Tharp & Gallimore, 1988). Extending the idea of engagement to all children requires teachers to view their students through a wide-angle lens. Some children with disabilities may need to learn how to initiate activities or how to remain actively involved with age peers. Others may need to learn that their behavior can influence their environment. Although the concept of engagement and active learning is important for all young children, how this concept is translated into action may vary for children across the classroom.

Indicator #8: Reflective Teaching

Teachers who are responsive to the diverse needs of children are reflective about their teaching practices (Schon, 1983). Teachers must become good observers of their own behavior, as well as of the behavior of their children. This type of thoughtful inquiry allows teachers to study individual child behavior within the context of the learning environment. Acknowledging that the same learning environment will affect students differently is the first step in becoming a reflective practitioner who can support inclusion.

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Indicator #9: Multiple Ways of Teaching and Learning

Teachers who support diverse learners are more likely to use a variety of teaching and learning strategies that challenge the strengths and support the needs of their students. Children in these classrooms are encouraged to use multiple methods to solve problems. Teaching approaches are selected for a "goodness of fit" between the teacher and the learner (Thomas & Chess, 1977). If any student does not master a specific skill, this situation is viewed as an inappropriate match between teaching method and student needs—it is neither a teacher failure nor a student failure. Alternative strategies are used to support alternative response modes (such as verbal rather than written, or pictures rather than words) whenever these best match learning needs.

Where Does It All Lead? A Portrait of Grace

Grace and four of her friends are graduating from their multi-age preschool class. Grace's preschool is inclusive, and her class represents a wide spectrum of interests, cultures, and abilities.

Grace has Down Syndrome. She participates in all parts of the curriculum in her inclusive classroom and, because of her individual needs, her program also includes speech and physical therapy. But Grace's therapy does not look like the traditional "pull-out" or one-to-one sessions with a professional: Her therapists are collaborative team members with her teacher, and they spend time in her classroom each week. A few weeks ago, Grace and three friends were hopping in rain puddles on the playground, along with Grace's physical therapist. After recess, the physical therapist explained to a parent volunteer that Grace was working on putting weight on one leg. "It looked like you were having fun," remarked the parent.

Grace's official record also says that she has limited verbal communication, and a visitor would realize quickly that her language level is not the same as most of her classmates. But Grace can communicate very effectively with her peers and teachers through the use of one and two word phrases and gestures. Grace's speech therapist has consulted with her parents and her teacher to select new vocabulary items for her that she will be motivated to learn because they connect her with her family, friends, and the community. In her inclusive classroom with many friends who can understand her and provide her with language models, Grace has much to talk about and many children to talk to. And because two of Grace's classmates speak a language other than English as their first language, the increased sensitivity and additional services in this inclusive program have benefited children other than Grace whose language needs are slightly "different."

Grace likes to be with her classmates. She often greets other children in the classroom with hugs when they arrive in the morning, and will often hold hands with a friend during songs or stories. The classroom is a busy place, and Grace is usually hard at play all day long. Her favorite areas of the classroom are the dramatic play area, the sensory table, and the manipulative corner.

In preparation for her transition, Grace's team—her teacher, her parents, the speech and physical therapists—discussed the changes they had seen in Grace over the last three years. Her communication and motor skills had improved. She had become much more independent in the classroom and had learned classroom routines, schedules, and the many rituals of schooling. What seemed most important to everyone was that Grace's personality had really come alive in the past few months. Everyone, including Grace, was looking forward to kindergarten.

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IDEA Update

BY MARCIE ROTH

TASH has been an integral part of an ongoing effort to join with parents and other grassroots disability rights advocates, disability-related service providers and education groups in a series of meetings scheduled by the Congressional Working Group on the Individuals with Disabilities Education Act (IDEA). This group is headed by David Hoppe, Chief of Staff for Senate Majority Leader Trent Lott (MI).

Other Working Group members include aides to Senators on the Committee on Labor and Human Resources and aides to Representatives on the Subcommittee on Early Childhood, Youth and Families. Judy Heumann, Assistant Secretary for the US Department of Education, Office of Special Education and Rehabilitation Services (OSERS) and Tom Hehir, Director of the US Department of Education, Office of Special Education Programs (OSEP), are also group participants.

During these meetings, TASH staff, members and many of the groups aligned with our position, have taken a strong stand with regard to the need to preserve the civil rights of all children with disabilities. This can only be accomplished by:

- leaving Part B of IDEA intact;
- re-authorizing the discretionary programs designed to make IDEA effective;
- permanently authorizing early childhood education; and
- increasing funding for IDEA implementation

Along with these recommendations, it has been the position of the TASH Governmental Affairs Operating Committee, as well as many grassroots parent groups and other disability groups across the country, that improved enforcement of current law will yield far better results for children, families and their communities than any proposed changes have any hope to. There has been wide agreement that the problem with IDEA is a problem of effective implementation and enforcement and not a problem with current law.

After many discussions with the Working Group about TASH's position, I extended an invitation to the principal of my neighborhood school, Tom Shade, to travel to Washington and address the Working Group regarding his perspectives on including and successfully educating all of the children in the neighborhood (see Principal Shade's comments beginning on Page 12).

Principal Shade's compelling comments were well received and a subsequent invitation to visit the school was accepted by David Hoppe, who is the father of a child with Down Syndrome, Tom Hehir (OSEP), staff aides to Senator Dodd (CT), Representatives Kildee (MI), and Castle (DE) and Congressional Fellow, Mark Hall, who works with Senator Lott's staff and is also the father of a son with Down Syndrome (fully included in his neighborhood school!). The visit was intended to show the success of a school which had received technical assistance from the MD Coalition for Inclusive Education's Neighborhood Inclusion Project, which receives funding through the US Department of Education and the Maryland State Department of Education.

The visitors and I spent four hours touring the school with Principal Shade, Dr. Barbara Gruber, of the Neighborhood Inclusion Project, Lee Murphy, Regional Administrator for the MD State Department of Education, as well as a local school board member and a Board of Education staff member. The visitors took every opportunity to speak with students and teachers and to see students with and without disabilities educated together throughout the school. The visitors were clearly excited by what they saw, and we hope their experience will guide them as they work with families and communities to influence the future of education for all children.

Comments of
Thomas H. Shade, Principal, New Market Elementary School
before the Congressional Working Group on
IDEA

Mr. Shade has been a principal and administrator for 27 years in the Frederick County, Maryland public school system.

Four years ago, New Market Elementary School was told that it would be a project school for inclusion. Money came from the U.S. Department of Education, to the Maryland State Department of Education, to the people working the Neighborhood Inclusion Project (N.I.P.).

I was not familiar with the term inclusion as it relates to children with disabilities, or the laws governing inclusion. At that time, children with severe disabilities in our county went to a special school. What I realized after a series of planning meetings with the children and their parents, was that our school could became the regular, everyday school for some kids who happen to talk, walk, and learn a little differently than we were used to.

I met Valerie, who has Down Syndrome, Sam, Kyle, and Brian, who have autism, Genna and Chaz, who have cerebral palsy, Christy, who uses a wheel-chair, and Lauren, who is legally blind and paralyzed on one side of her body. Seven of these young children still remain at our school, while one has gone on to middle school.

Before continuing, I think it's important to tell you about our school. New Market Elementary School is in eastern Frederick County. Our kindergarten through grade 5 school capacity is 560 students; we currently have 964 students. We have thirteen portable classrooms outside on our playground and we are operating at 158% of capacity. We are the most over-crowded school in Frederick County. Despite the high numbers, we feel it is important to include, and we actively sought out, kids who lived in our school district but were attending a special school for children with disabilities.

In the four years since the children have become a part of the school, I have observed many extraordinary things. Brian was 7 years old when he came to us. He was shy and withdrawn, partly because he was new to the school and partly because he was surrounded by more kids than he had ever seen before. He made guttural sounds and only echoed back words that he heard others say. He is now 10 years old, talks in complete and understandable sentences, finds his way anywhere through the school, follows directions, completes school assignments and, just this week, did a dance routine with another student in our school talent show. He also gets invited to parties, something his mother said never happened until he came to his neighborhood school. Quite honestly, Brian has probably taught the other students more about diversity, acceptance, and disabilities than we have taught him. Brian does have an instructional assistant to help him because, in most areas, he needs modifications made to his lessons.

I could give you dozens of anecdotal happenings of success stories with all of the children. Our teachers have overwhelmingly accepted them. At every grade level, teachers *ask* to have one or more students with disabilities placed in their rooms. We have never had a due process situation go past our school level. We have also never had parents complain about who their children have been placed with. And we've never had a serious behavior referral on any of our students with disabilities that we could not handle.

Because of the support of the N.I.P., we had the advantage of in-service training that really gives teachers what they need to teach to a diverse classroom. Through N.I.P., we have also gotten expert behavioral support personnel to visit and give advice in challenging situations. Our teachers have been trained individually and as teams, so that transitions can be made easily at each grade level.

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Comments of Thomas H. Shade

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In order to meet the needs of the students, we desperately need the kind of trained pre-service instructors who know how to teach to diverse populations. The N.I.P. has provided us with resources, time, and expert help; most of the rest of the schools in our county have not had any pre-service or in-service training.

I am not knowledgeable about all the fine points of the law related to inclusion, but I do know that the current law has not hindered me or my staff in any way.

I know that we can teach youngsters with disabilities. I know in my heart that they belong in our (and their) neighborhood schools, and I wish I would have met them sooner than four years ago. They have diversified, energized, sensitized, and light-a-fired me. I am proud to be here today to help advocate for them.

Congressional staff and others visit New Market Elementary School

The Complexities of Community-Building

July 15-16, 1997 ❖ Syracuse, NY

Make a Note of It!

Facilitators: John O'Brien, Connie Lyle O'Brien, Beth Mount, Steve Taylor, Bonnie Shoultz, Michael Kennedy, Pam Walker, and other Center on Human Policy Staff Members

Location: Genesee Inn, 1060 E. Genesee St., Syracuse, NY 13210
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Workshop: For further information about the workshop contact Pam Walker, Center on Human Policy, 315-443-3851 or email: pmwalker@mailbox.syr.edu

A workshop co-sponsored by TASH and the Center on Human Policy

THE EARLY CHILDHOOD INCLUSION NETWORK:

One Community's Efforts to Promote Child Care Inclusion

DIANNE APTER AND PAM WALKER

How The Inclusion Network Got Started

It became apparent to some service providers in Onondaga County, New York, in the late 1980s, that few children with special needs were in child care centers in the community. There were some examples of inclusion, but, at that time, many children with disabilities were in separate programs. The Early Childhood Inclusion Network of Onondaga County came together in 1991 through the initiation of a few special education program directors who also happened to be on the board of the county Child Care Council, which provides technical assistance to the child care community. From the beginning, participants included representatives from special education and from child care, a representative from the university-based Early Childhood Direction Center, a representative from the Health Department, and a few others.

Members of this task force shared a strong commitment to inclusion. They felt that the effort to expand inclusion in child care settings needed to be a team effort; for example, it couldn't be just "dumping" kids into child care. They felt at that time that they really needed to communicate with each other. Thus, they began what ultimately became the Early Childhood Inclusion Network.

Parallel to this, there was a statewide task force that met in Albany, New York. This group consisted of similar players, but also included the appropriate people from state divisions (Department of Education, Department of Health, Department of Social Services, and Council on Children and Families). A representative from the Early Childhood Inclusion Network, who was also part of the state coalition, served as a liaison between the two groups.

Getting to Know Each Other

The Early Childhood Inclusion Network began by spending a lot of time

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THE EARLY CHILDHOOD INCLUSION NETWORK

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getting to know each other and sharing viewpoints on various issues. Child care people talked about at times feeling devalued by special educators, who might come into their child care center, assist a child, and then walk out without acknowledging the child care staff at all. Special education representatives talked about how they would go into the child care center to work with the child or children, and how the child care teacher would say 'oh, good,' and think that that meant that relief had come and she could leave, and she'd walk out of the room. Network members were pretty honest with each other. In addition to the problems, however, people also talked about the positive things that were happening in the community, the good partnerships, what they were learning from each other. The "getting to know each other" phase went on for a couple of months, without a lot of focus. This phase in the development of the group was crucial to building trust and respect.

Identifying and Addressing Barriers to Inclusion

After the task force had been meeting for a while, a representative of the statewide coalition came to the county to do a focus group on barriers to inclusion. Members of the task force had already spent some time thinking about this; therefore, at the focus group, people were able to identify some key barriers to inclusion. Some of these were related to transportation. For example, child care runs all the time, but special education goes on school breaks, so the bus drivers for children with special needs have to be informed of these schedule differences. Or, at school, the bus drivers wait at the curb and special education assistants bring children out to the bus; but child care doesn't have relief staff to take somebody out to the bus. So, what seems on one level, to be a small problem, can be a very large one. "This kid can't be here if we can't get her to the bus, the bus driver refuses to come in to the child care center because that's not his job, and the child care center can't leave the kids alone to go out to the curb." We're talking about 20 feet, and it presents this seemingly insurmountable barrier. Things like this came out that were important to talk about.

At that point, members of the task force decided that they wanted to develop a couple of foci. The state education department had come out with "innovation waivers." These waivers allowed communities to apply to do something differently, to waive a regulation, as long as what you were proposing got their approval, and as long as it didn't cost any more money. Basically, the waivers were intended to address state regulations that got in the way of inclusion. The task force received approval for three different waivers.

The first waiver addressed an issue related to itinerant special education teachers. A state law specified that approved special education programs were the only programs that could employ itinerant special education teachers. While the county was allowed to hire physical therapists (PTs), occupational therapists (OTs), and speech therapists for "on the road" teams, they couldn't hire teachers. A waiver allowed the county to hire a teacher as part of an itinerant team.

The second waiver applied only to special education preschool programs based in public schools. It allowed them to hire pre-K teachers at a salary commensurate with that of child care teachers and waive the requirement that they hire certified teachers. A certified special education teacher would still be the lead teacher in the room.

The third waiver dealt with the teacher/child ratios. It allowed a slightly higher ratio of students to teacher/paraprofessional (15:1:1, versus 12:1:1). At the same time, it proposed a limit on the ratio of special needs/non-special needs children, in order to protect against creation of classrooms of only children with special needs.

"Can We Talk?" Retreats

In addition to the waivers, the task force sponsored two retreats, 9 months apart, called: "Can We Talk?" and "Where Do We Go From Here?" "They were very successful; we used outside facilitators; lots of people came, and we really focused on issues related to building partnerships and teams, barriers to working in teams, and how to communicate." The first one was oriented more toward expressing feelings and perspectives; the second one was much more goal-focused.

Both retreats attracted a mix of special education and child care representatives. Among the child care representatives, there were a variety of people from both not-for-profit and for-profits settings, and from urban and suburban settings. "Some came because they were already doing inclusion, some because they were intrigued by the idea, and some because of concerns about being mandated to do so by the ADA."

The time together at the retreats was critical. Participants gained a much greater understanding of each other. For instance, they realized differences in the pace of their daily activities and involvements with children. While the child care center teacher is there all day long with the same children, the special education teacher comes in for only an hour or two of intensive work. At times, the special education teacher would react with, "Come on, you're not on top of this enough; you're not doing such-and-such a developmental activity." The child care teacher would respond with, "Calm down, yes, we do do that." Those involved in the retreats seemed to come away with a different way of looking at

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things, with greater appreciation for each other. Special educators increased their understanding of different styles related to support and learning which may be used by child care providers; and child care providers realized that they did have valuable knowledge and expertise which could be utilized in support of children both with and without disabilities.

Developing a How-To Manual for Child Care Providers

At the retreat, child care providers talked about not knowing how to start doing inclusion—who to talk to, what to do first. Thus, one of the outcomes of the retreat was a decision to compile a manual for child care providers related to inclusion strategies and issues. A subcommittee was formed to work on the manual, with representatives from child care, special education, and the Early Childhood Direction Center. They decided they wanted the content of the manual to come from the perspective of those who had been doing inclusion in the community, incorporating their suggestions for what works, what doesn't work, and so forth. Two student interns interviewed a wide range of people, including child care directors and staff, special education directors, teachers, and assistants. During the process of preparing the manual, child care people kept saying, "Keep it simple; keep it short." The committee compiled the data and developed an outline and rough draft; a graduate student pulled everything together and edited the final draft of the manual, "Serving Children with Special Needs in Your Child Care Facility." This manual discusses the benefits of inclusion; describes elements of successful collaboration; and provides detailed information about setting up collaborative, inclusive programs (e.g., philosophy, lines of authority, money and contracts, schedules, space and accessibility, meetings, staff development, family involvement).

Lessons and Future Directions of the Inclusion Network

There are a number of lessons that emerged from the efforts of the Early Childhood Inclusion Network. A few are outlined below.

1. It is critical that child care providers are empowered and supported to include children with disabilities. However, finding time to release child care staff to be part of interagency, community-wide discussion and planning is difficult. In addition, sending child care staff to a workshop to learn about children with special needs is not sufficient training, in itself; on-site technical assistance is also needed—and the availability and quality of this is variable.

2. It is critical that representatives from child care and special education come together to learn about each other's perspectives and formulate strategies for working together. Those involved in this project generally didn't have a lot of training or practice in such interdisciplinary collaboration and team work. It is important that teacher preparation programs increase their emphasis on training in these areas.

Within the region, there are now many more people doing inclusion than ever before. Many programs have increased their capacity to support children with more severe disabilities. To a much greater degree than previously, there is shared ownership for inclusion, where all children are seen as "ours," versus some as "yours" and some as "mine." Currently, there is a greater push from the state to move in the direction of inclusion and close segregated programs. Child care providers are concerned about possibly being overwhelmed by having too many children with too many needs and too little support; and fiscal support for child care centers is still lacking. Thus, the Early Childhood Inclusion Network will focus on issues related to planning and implementing increased inclusion in ways that maintain quality child care programs for all.

* * *

For further information about the Early Childhood Inclusion Network, contact Dianne Apter, Director, Early Childhood Direction Center, 805 S. Crouse Ave., Syracuse, NY 13244.

To order the manual, send a check or money order in the amount of $6.95 to: Rachael Zubal, Center on Human Policy, Syracuse University, 805 S. Crouse Avenue, Syracuse, NY 13244-2280.

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TASH Early Childhood Interest and Action Group

FOCUS ON EARLY ADVOCACY

BY BETH BRENNAN

The last twenty years have seen unequaled advancement in legislation and service provision for very young children with significant disabilities. The inclusion of families and caregivers into this legislation and service provision is a major part of that advancement. For young children who can not advocate for themselves, the power of their families and caregivers to advocate for them frames in great measure the paths that are available to them in both their early and later years. The historical focus on advocacy within TASH points to this organization as an effective starting point for families and caregivers of children with significant disabilities in their quest for advocacy, education and support.

The TASH Early Childhood Interest and Action Group will focus on Early Advocacy as a central topic in planning for the TASH conference in Boston in December. During an Early Childhood meeting of professionals and family members in New Orleans, several other important areas of interest emerged including:

- The inclusion of children with severe disabilities in community child care programs
- Preschool issues
- Parent support
- Special education laws regarding Early Childhood settings
- Transition from Part H to Part B programs

Further discussion at this meeting produced two goals for the Early Childhood Interest and Action Group. The first goal is one directed toward connecting families of young children with severe disabilities with TASH. The second goal is to increase awareness of the issues specific to the inclusion of young children with severe disabilities in natural community and preschool settings.

The Early Childhood Interest and Action Group welcomes the contribution of professionals, family members and self-advocates who have an interest in Early Childhood issues. Critical to your efficacy as a group is the participation of self-advocates and family members who have worked their way through the system and can lend support and information to parents and professionals who are new to the system.

For more information on the TASH Early Childhood Interest and Action Group, contact:

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San Francisco State University
1 Tapia Drive • San Francisco, CA 94132
Phone (415) 338-1590 • FAX (415) 338-3525

Rich Villa
&
Norman Kunc

The Inclusion Puzzle

Fitting The Pieces Together

A Two-Day Workshop on The Philosophy, Instructional Strategies, & Organizational Practices of Inclusive Education

Participants will learn about:

- The essential attributes of successful inclusive schools.
- The relationship of inclusion to other school reform initiatives.
- How to build a sense of belonging and mastery within increasingly diverse schools.
- Collaborative teaming and creative solution finding processes.
- Curriculum adaptation tools which simplify the process of modifying lesson plans to suit a student's individual needs.
- How to provide a fair evaluation for those students who use a modified curriculum.
- What types of classroom and school based support are most helpful to teachers
- Changing roles, roles and relationships among adults and students in inclusive schools.
- How to work with circles of support without having students adopt attitudes of charity and benevolence.

May 8th & 9th, 1997

Radisson Hotel - Lisle - Naperville, Illinois

For more information, contact

Mark Doyle at Everyone Is Welcome: 630 584-0970

VIRGINIA COMMONWEALTH UNIVERSITY REHABILITATION RESEARCH AND TRAINING CENTER ON SUPPORTED EMPLOYMENT

Title: Supported Employment Handbook: A Customer-Driven Approach for Persons with Significant Disabilities

Edited by: Valerie Brooke, Katherine J. Inge, Amy Armstrong, and Paul Wehman

The purpose of this manual is to provide a contemporary training resource on implementing supported employment using a customer-driven approach. This is a model that works when the customer directs the process. We must be prepared to support the customers of supported employment to obtain the careers of their choice. - *Paul Wehman*

This comprehensive handbook will provide detailed information and techniques on such topics as:

Organizational Marketing
Developing a Customer Profile
Directing the Job Hunt
Knowing the Job Seeker
Promotional Tools
Crafting the Job Search
Job Accommodation
Job Restructuring
Job Analysis
Task Analysis
Natural Supports
Natural Cues
Instructional Strategies
Self-Management
Job Site Modifications
Assistive technology
Fading From the Job Site
Long Term Supports
Employment Mentors
Funding Support and Services

This handbook can be purchased for $21.95, or to receive more information and a free brochure contact Teri Blankenship at (voice) 804/828-1851, (TDD) 804/828-2494 (fax) 804/828-2193, & (e-mail) tcblanke@saturn.vcu.edu . VCU is an EEO/AA University, if accommodations are needed contact Teri Blankenship.

Community Health Leadership Program

The Robert Wood Johnson Community Health Leadership Program honors ten outstanding individuals each year for their work in creating or enhancing health care programs serving communities whose needs have been ignored and unmet. Each leader receives $100,000, which includes a $5,000 personal stipend, and $95,000 for program enhancement over a three-year period.

The Community Health Leadership Program (CHLP) seeks out individuals who have the leadership skills to overcome complex obstacles and find creative ways to bring health care services to their communities. All are largely unrecognized and in "mid-career", most often with no less than five and no more than fifteen years of community health work experience.

•

The nomination process is open and nominations can be made by consumers, community health leaders, health professionals and government officials who have been personally inspired by the nominees.

•

Interested nominators can write CHLP anytime for a brochure and a *Letter of Intent* form (LOI), due to the Program Office no later than September 16, 1997. Early submissions are guaranteed a prompt response.

•

For additional information, please contact CHLP, 30 Winter Street, Suite 1005, Boston, MA 02108.

TASH CHAPTER *News & Views*

BY LINDA RAMMLER

This is the first of what we hope will be a permanent column in the TASH *Newsletter* dedicated to the chapters of TASH. In this column, we will feature TASH chapters, report on activities of the Chapter Operating Committee (COC), and provide valuable information to TASH chapter members. We are currently putting into place a process to be used to gather information from chapters in a timely manner about upcoming conferences and other news.

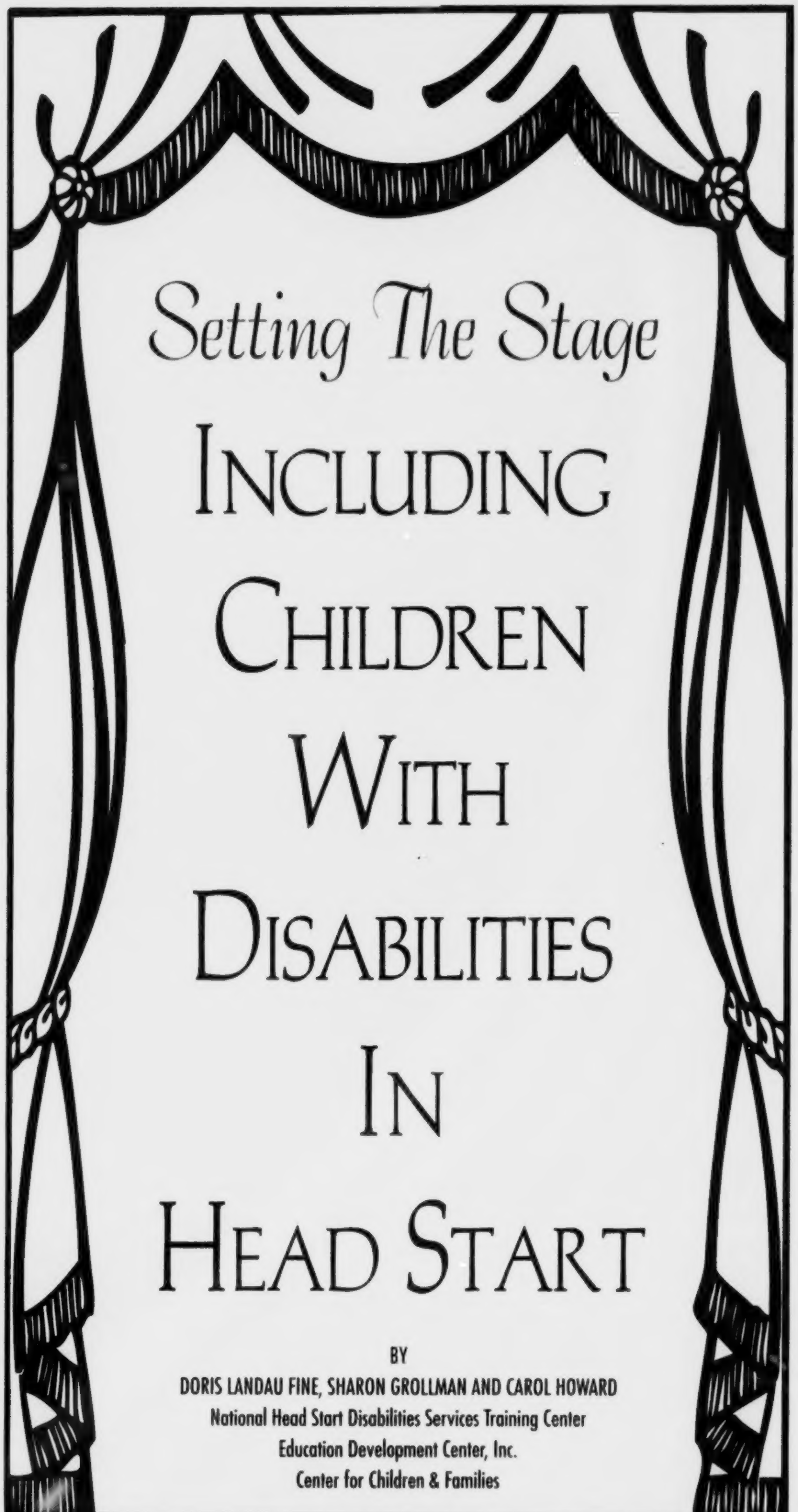
The TASH annual conference in New Orleans was an exciting time for chapter members, both to enjoy the conference and to have an opportunity to revitalize interest and commitment to the grassroots of our organization. A luncheon for chapter officers, held on Wednesday between TASH Tech sessions, provided an opportunity to dialogue openly with TASH's Executive Director, Nancy Weiss, and Frank Laski, TASH Board President, about some of the issues that have been of concern to many chapters.

During the course of the conference, the COC met several times. At these meetings, the results of a survey that had been distributed to chapters last fall were reviewed; chapter and national relations were discussed; and a strategic plan for the COC drafted. Highlights of the outcomes, which were shared with and accepted by the TASH Board of Directors at its meeting during the conference, were as follows:

- The COC will work to clarify the role of chapters within TASH by reviewing the current by-laws and prior board activities related to chapter representation for reconsideration by the Board at its Spring 1997 meeting (to be held in June).
- A leadership training session for TASH chapters is being planned for the 1997 annual conference in Boston. Chapter members are invited to contact Linda Rammler, COC Chairperson (1-860-349-7083 or e-mail rwc@connix.com) or Nancy Weiss (1-410-828-8274, ext. 101 or e-mail nweiss@tash.org) with ideas for session content.
- The COC will work with the Board to define avenues for regular chapter-national contact and increase communication within TASH as a whole. More on this topic will appear in subsequent Chapter News articles.

The last couple of years has seen some very positive momentum develop between the COC and the national office. The COC is committed to assuring that chapters and representatives continue to work with the national office to foster growth and positive change. This momentum includes continued implementation of the plan for paying chapters dues money owed from previous quarters, continued accessibility to the Executive Director and the TASH staff, and continued receptivity of the Board to chapter concerns.

For further information about the details of the Chapter Operating Committee, to let us know about issues of concern to you, or to share the great things your chapter is doing, please contact Bill Gorman, Editor-TASH Chapter News and Views, 1556 First Avenue, South Iowa City, Iowa 52240 or Linda Rammler, Chair, TASH Operating Committee, 6 Way Road, Suite 301, Middlefield, CT 06455.



Setting The Stage

INCLUDING CHILDREN WITH DISABILITIES IN HEAD START

BY

DORIS LANDAU FINE, SHARON GROLLMAN AND CAROL HOWARD
National Head Start Disabilities Services Training Center
Education Development Center, Inc.
Center for Children & Families

Four-year-old Jenny watches as Danny, a classmate, carefully traces his hand with a neon-green marker. Jenny's arms end at her elbows. "Wanna borrow my hand?" Danny asks her. "That's okay," Jenny says. "I'll just use my own." Then they both trace their hands together.

Increasingly, this is becoming a typical scenario as Head Start programs are reaching more children with significant disabilities. It is not surprising. Head Start has been a pioneer in including children with disabilities—reaching and serving children with disabilities before any federal educational mandates existed. In fact, Head Start has become a major provider of services for young children with disabilities and their families, with increasing enrollments since the 1970's. In 1994, Head Start served about 96,000 children with disabilities (Project Head Start Statistical Fact Sheet, 1995).

Head Start also demonstrated its ongoing commitment to children with disabilities and their families when they earmarked funds for the National Head Start Disabilities Services Training Center. This contract was awarded to Education Development Center, Inc. (EDC) in 1993. As training specialists and writers for the National Head Start Disabilities Services Training Center, our mission is to develop a series of five comprehensive training guides to assist Head Start grantees in their staff development efforts to serve children with disabilities and their families.

As a first step in the materials development process, we conducted extensive interviews and focus groups with personnel from all levels of Head Start across the country. Through these conversations we learned about the creative ways that staff are already involving families and how they are

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SETTING THE STAGE

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making classroom adaptations so that all children can participate. We also learned that Head Start staff need more support and training as they build and nurture alliances with other service systems, especially as they serve children with more significant disabilities.

The training guide series, which will be completed in 1997, was developed in response to the needs expressed by Head Start programs nationwide. Guides in our series include:

- Setting the Stage: Including Children with Disabilities in Head Start
- Leading the Way: Disabilities Services and the Management Team
- Supporting Children with Challenging Behaviors: Relationships are Key
- Translating the IEP into Everyday Practice
- *Including Children with Significant Disabilities* (working title)

Each guide contains training modules which include workshops and coaching sessions. These activities offer a range of experiences such as role playing, assessing existing facilities, interviewing colleagues, analyzing cases, as well as openly discussing challenges and sharing successes. In addition to step-by-step instructions for trainers and handouts for participants, the guides offer ideas for continuing professional development and annotated resources.

The first guide in the series, *Setting the Stage, Including Children with Disabilities in Head Start*, has recently been published and distributed to Head Start programs across the country; it is also being used as case material for community college courses. This guide, designed for all early childhood staff, parents, and consultants, reinforces the effort necessary to include children with disabilities and their families in all aspects of the program. Activities help participants identify ways in which their own experiences influence how they interact with children with disabilities and their families; identify and practice ways of communicating about disabilities that foster a sense of belonging; and identify ways to provide additional supports necessary to fully integrate children with disabilities into their programs.

We hope that taken together, our guides will support Head Start's efforts to expand their capacity to reach and serve children with more significant disabilities and their families into the next century.

Ordering Information

If you are affiliated with a Head Start program, you can receive a free copy of our guide *Setting the Stage: Including Children with Disabilities in Head Start*. You can also receive free copies of the other four guides as they become available. Simply fax an order form or your order on program letterhead, with the director's signature, to the Head Start Publication Center in Alexandria, VA at (703) 683-5769.

If you are not affiliated with a Head Start program, you can mail your order to:

Superintendent of Documents
U.S. Government Printing Office
P.O. Box 371-954
Pittsburgh, PA 15250-7954

REFERENCE

U.S. Department of Health and Human Services (Feb., 1995). *Project Head Start statistical fact sheet.* Washington, DC: U.S. Department Government Printing Office.

TASH Newsletter

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INSIDE FRONT AND BACK COVER, ads can be placed on a space-available basis. Same size requirements as a full page ad.
Regular Issue: $450
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Camera-ready ads preferred. Ads should be 85-100 line velox or 85-120 line negative.

Ad copy is subject to review and approval by TASH.

DEADLINE for submission of Newsletter Advertising is the FIRST FRIDAY of the month prior to the month of publication. *(For example, the first Friday in March for April's issue)*

CONTACT:
Priscilla Newton, Director of
Member Services
TASH National Office
29 W. Susquehanna Ave., Suite 210
Baltimore, MD 21204
Phone: (410) 828-8274, ext. 102
FAX: (410) 828-6706
E-mail: pnewton@tash.org

P.L. 99-457 REVISITED:

DO FAMILIES REALLY HAVE MEANINGFUL OPTIONS?

It has been over ten years since the passage of the landmark legislation, P.L. 99-457, a law which has significantly changed the face of services for young children with disabilities and their families. This law, now part of the Individuals with Disabilities Education Act (IDEA, 1990), has shed new light on the centrality of families in the lives of young children. Families now have more freedom to make choices and more opportunities to be involved.

But do families really have a full range of opportunities to make meaningful decisions regarding the delivery of early childhood services to their infants, toddlers and preschoolers?

The following ten questions are posed to provide a platform for discussion about the quality and integrity of options provided to families of young children with disabilities a decade after the passage of one of the most important pieces of early childhood legislation.

There is no question that the availability of programs and the number of personnel qualified to serve young children and their families have expanded. But given this increase, it still remains to be seen whether or not the spirit and purpose of P.L. 99-457 has been realized. Until families, regardless of where they live, can access high-quality and individually tailored services in a way that reflects a deep respect for their choices, then the intent of P.L. 99-457 may not have yet been reached.

Elizabeth J. Erwin, Ed.D., is Co-Chair of the TASH Early Childhood Interest and Action Group. For further information, please contact her at Queens College of the City University of New York, School of Education/ECP, Flushing, NY 11367.

1. **Are families provided ready access to affordable and high-quality services in natural environments? (Some families still need to pay tuition in community-based settings.)**
2. **Do families have a wide range of options where quality services are to be delivered (i.e., home, child care center, play group, Head Start, etc.)?**
3. **Do families have inclusive, community-based programs readily available to them (particularly families of young children with severe disabilities)?**
4. **Are families' values honored (i.e., decision to bottle- or breast-feed their child) and cultural beliefs respected?**
5. **Are families viewed as important members and contributors of the team?**
6. **Are families encouraged to have meaningful roles in planning, implementing, and evaluating their child's IFSP (Individual Family Service Plan) or IEP (Individual Education Program)?**
7. **Are families routinely an integral part of the program evaluation process?**
8. **Are families given the opportunity to assume meaningful roles in a variety of activities related to their child (i.e., transition, assessment)?**
9. **Do families and professionals have a relationship built on trust, collaboration, and mutual respect?**
10. **Are families satisfied with their participation in their child's education?**

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1997 TASH AWARDS

IT'S TIME ONCE AGAIN TO SUBMIT TASH AWARD APPLICATIONS!

Every year at the annual conference, TASH confers a series of awards that recognize individuals, teams, organizations, or media mediums which exemplify the spirit and mission of TASH. Submit your application (found on the following two pages) today!

▶Who comes to mind when you think of someone who has made a positive difference in the lives of persons with significant disabilities over the past year?

▶Have you recently seen an outstanding media piece that embodies the values of TASH?

▶Do you know of a student enrolled in a doctoral program in education or a related field who demonstrates leadership, advocacy, and commitment to efforts of individuals with disabilities?

▶Is there a team of people working together to improve the quality of life for a person(s) with disabilities?

This is your chance to honor such accomplishments with official recognition. Please take the time to submit an application. Awards will be conferred as part of the TASH Annual Conference to be held in Boston, December 10-13, 1997. Award applications will be accepted through July 31, 1997. **Please be sure to indicate for which award you are applying on the application, and submit all required documents or information requested for that award.**

1997 POSITIVE APPROACHES AWARD

This award is presented to the person whose contributions have served to advance non-aversive intervention with persons who display challenging behaviors; have demonstrated outstanding efforts leading to the understanding of challenging behavior, and whose actions have advanced the use of non-aversive interventions and progress in the use of positive behavioral supports.

1997 ALICE H. HAYDEN AWARD

This $500.00 cash award will be presented to a doctoral student enrolled in a program in education or a related field, who demonstrates potential for leadership in teaching, scholarship, and service on behalf of people with significant disabilities. The individual needs to have demonstrated a continuing desire in working in partnership with people with disabilities in accordance with TASH values.

1997 MEDIA AWARDS

This award is presented to honor presentations in either print or film, which best promote the inclusion of people with severe disabilities in all aspects of community life, and which have reached a national audience. Criteria for selection include: high quality, accuracy of information, meaningfulness of subject matter, potential for consciousness-raising, and promotion of quality of life for persons with disabilities.

1997 COLLABORATION AWARD

TASH will recognize collaborative teams of persons with disabilities, family members, professionals, community members and or peers, who are engaged in projects and advocacy efforts to ensure the implementation of TASH values in their local community, or in a way that has affected others at a local, state, regional, and/or national level. The work of the recipients of this award should serve as an inspiration for other community efforts, and demonstrated creativity in supporting an individual or individuals to realize the goals of self-empowerment and full community inclusion.

For more information, please contact Denise Marshall at 1-800-482-8274 x103.

1997 TASH AWARD APPLICATION

- Applications due July 31, 1997 -

How to Apply:

(1) Complete this application form - front and back- as fully as possible.

(2) Attach a brief narrative discussing why the nomination is being made. Please see the other side of this form for a list of supporting information and materials that must be submitted for the particular award you choose below.

3) Please indicate for which award you are applying. **Check only one award.**

- ☐ Alice H. Hayden Award
- ☐ Collaboration Award
- ☐ Media Award
- ☐ Positive Approaches Award

(4) To be considered, the original completed application and supporting materials must be received in the TASH central office no later than July 31, 1997. Send to:

Awards Committee
TASH
29 West Susquehanna Avenue
Suite 210
Baltimore, MD 21204

(5) Questions concerning this form should be directed to Denise Marshall, (410) 828-8274 x103.

Person or Team Being Nominated:

Name of the Individual:

Street Address:

City:

State/Province: Country

Zip/Postal Code:

Daytime Telephone: ( )

Evening Telephone: ( )

Is this individual(s) a member of TASH?
☐ **Yes** ☐ **No**

Name of team members (more room on reverse side)

Street Address:

City:

State/Province: Country

Zip/Postal Code:

Daytime Telephone: ( )

Evening Telephone: ( )

Is this individual(s) a member of TASH?
☐ **Yes** ☐ **No**

Person Making the Nomination:

Name:

Relationship to the team/person:

Street Address: **City:**

State/Province: **Country** **Zip/Postal Code:**

Daytime Telephone: ( ) **Evening Telephone:**

FAX:( ) **E-mail:**

Please provide as much information as possible about the persons who are part of this team. Please use additional paper if necessary.

Name of Team Member:

Organization if applicable):

Street Address:

City:

State/Province: Country:

Zip/Postal Code:

Daytime Telephone: ( )

Evening Telephone: ( )

Is this individual(s) a member of TASH?
☐ Yes ☐ No

***

Name of Team Member:

Organization (if applicable):

Street Address:

City:

State/Province: Country:

Zip/Postal Code:

Daytime Telephone: ( )

Evening Telephone: ( )

Is this individual(s) a member of TASH?
☐ Yes ☐ No

***

Name of Team Member:

Organization (if applicable):

Street Address:

City:

State/Province: Country:

Zip/Postal Code:

Daytime Telephone: ( )

Evening Telephone: ( )

Is this individual(s) a member of TASH?
☐ Yes ☐ No

***

MEDIA CONTACTS

Please provide on a separate sheet of paper, the names and addresses of local radio, television, or newspaper outlets that would be interested in covering the presentation of the award.

AWARD APPLICATION REQUIREMENTS

Collaboration Award:

1. Attach a narrative which describes: a) the goal of the team; b) the interaction of the team members; c) the roles of the individual himself/herself, the family, peers of the individual, and/or people who provide paid support; d) the outcome of the team's efforts; and e) a brief narrative about the individual or individuals who benefited from the collaboration.
2. Attach at least three (3) letters which support the nomination. These letters should present specific anecdotal information or data which conveys an accurate picture of how this collaborative effort met the criteria for the award.

Positive Approaches Award:

1. Attach a description of the nominee's background in the area of severe disabilities. Please include a resume/curriculum vitae if appropriate.
2. Attach evidence of contributions related to positive behavioral support.
3. Attach three (3) separate one page letters in support of the nomination.

Alice H. Hayden Award:

1. Attach a curriculum vitae outlining your history of:
   a) higher education (including major, minor, degree, date of completion); b) employment (including dates, duties, name of supervisor); c) research and publications.
2. Also attach 500-1000 word essay which describes:
   a) your current work on behalf of individuals with severe disabilities; b) your educational and professional objectives.
3. Attach at least three (3) letters which support the nomination. These letters should be from professors who are familiar with your qualifications. The letters should present specific data or anecdotal information which convey an accurate picture of your current achievements and potential for significant contributions to the field.

Media Award:

1. Please provide a brief description of the project, including the medium used (radio, television, newspaper, magazine):
2. If the nomination is in the film category, please indicate the length of the video in minutes.
3. Attach two copies of the nominee's work, or of the specific project being nominated. If the nomination is in the print category, the submission must be neat and legible. If the nomination is in the film category, two video copies (VHS 1/2") must accompany the nomination. The submitted work must be sufficient to demonstrate that the work meets or exceeds the criteria for the award.

Permission to show video submittals:

If the nomination is in the film category, please complete and sign the following to hereby grant permission to TASH to show:

(Title),

as produced by ,

for, but not restricted to, promotion of the TASH Media Awards and the 1997 Annual Conference. Similarly, as it applies to the promotion of the TASH Awards and the 1997 TASH Conference, the producers waive any monetary compensation .

Signature:

The University of Washington Graduate Program trains teachers to serve the needs of pupils with significant disabilities. Emphasis on data-based, systematic instruction referenced to the requirements of natural school and community settings. M.Ed. degree plus initial teacher certification possible.

Dr. Felix Billingsley, Area of Special Education,
102 Miller Hall, Box 353600, University of Washington,
Seattle, WA 98195, Phone (206) 432-1827,
e-mail felixb@u.washington.edu

DEVELOP AND VALIDATE YOUR SKILLS AND ABILITIES

1997 Cape May, N.J. Summer Workshops

June 16-20
Children Who Present Severe Challenges:

Faculty: Philippa Campbell, Ph.D., OTR/L, FAOTA, Richard Foxx, Ph.D. and Kathleen Stremel, M.A. Focus on individuals who are identified with labels such as autism, severe/profound intellectual disability and "hard to teach." Integrate techniques from various perspectives to design programs; assess and document strategies; and analyze programming situations to problem-solve and design successful programs for challenging children/students.

June 23-27
NDT and Other Approaches for Children with Movement Problems:
An Introductory Course:

Faculty: Philippa Campbell, Ph.D., OTR/L, FAOTA, Sarah Forsyth, OT/DIP. This hands-on course provides introductory information and practical applications of therapy interventions so that non-therapy personnel and family members may also learn the perspectives and strategies that therapist use to approach children's motor dysfunction; design and use adaptations and devices; and use facilitation/inhibition information from a therapy evaluation.

For more information and registration, contact:
Terri Thomas at (215) 204-1396

Special Education Service Agency (SESA)

Based in Anchorage, is looking for teachers with advanced training and experience to work independently and collaboratively with other professionals in cross cultural settings. Requires travel to rural and remote villages in Alaska. Prefer experience with teacher training and support and interagency networking.

Multiple Disabilities

Master's level special education teachers with specialized training and a minimum of three years recent experience in at least two of the following: multiple disabilities, autism, orthopedic and other health impairments, mental retardation, traumatic brain injury and preschool developmental disabilities. Working knowledge of inclusion, positive behavior supports, alternative communication, community-based instruction and/or vocational development is a must. Familiarity with current technologies in communications, productivity and education required. Salary range: $39,402 - $51,133 DOE

Contact:

Ron Jones, Program Administrator
2217 E. Tudor Road, Suite 1, Anchorage, AK 99507
(907) 562-7372 (voice) or (907) 563-8284 (TTY)

AXIS CONSULTATION & TRAINING, LTD.

340 Machieary Street, Nanaimo, B.C. V9R 2G9
(Phone) 250/754-9939 • (Fax) 250/754-9930

A Credo for Support (Video Presentation) - 4 Minutes

This powerful four minute video set to music offers a series of suggestions for people who care about and support someone with a disability. It prompts viewers to question the common perceptions of disability, professionalism, and support. Designed for use in presentations, in service staff training, and orientation programs, this video can be a provocative catalyst for a dialogue on these issues. Cost for VHS format Video: $25.00 plus postage.

Also, **A Credo for Support** is now available in poster format (18" x 24") for just $10.00 plus postage. Contact Axis Consultation about its other videos (most also available in audio format).

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on language "that emphasizes the humanity of people with handicaps." Terms such as "the autistic," "the retarded," and "the severely handicapped" refer to characteristics, not individuals. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Executive Board

Frank Laski, *President*
Mark Partin, *Vice President*
Liz Healey, *Chair of the Executive Committee*
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Mike Auberger, *Treasurer*
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Ian Pumpian
Carmen Ramirez
Linda Rammler

MEMBERSHIP INFORMATION

Funds must be submitted in U.S. Dollars.

Name: ______________________________

Address: ______________________________

City/State/Zip: ______________________________

Telephone: (   ) ______________ Fax: (   ) ______________

Please Check Appropriate Categories
(not more than three):

( ) Administrator
( ) Adult Service Provider
( ) Case Manager
( ) Day Personnel
( ) Early Childhood Services
( ) Educational Adult Services
( ) Educator (University/College)
( ) Early Intervention Specialist
( ) Friend
( ) Gov. Personnel (Federal, State, Local)
( ) Higher Education
( ) Human Services Provider
( ) Interested Individual/Advocate
( ) Legal Administrator
( ) Occupational/Physical Therapist
( ) Paraprofessional/Direct Care
( ) Parent/Family Member
( ) Primary Care Provider
( ) Personal Assistant
( ) Professional Advocate
( ) Psychologist
( ) Regular Education
( ) Residential Services
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Student (College/University)
( ) Support or Related Services
( ) Supported Employment Personnel
( ) Teacher (Direct Service)
( ) Teacher Trainer
( ) Vocational Services
( ) Other

General Membership (individual) .... $85.
Agency/business/university/college/library/school .... $190.
(allows three conference attendees)
Self Advocate, Parent, Full Time Student, Direct Careworker/Paraprofessional/Personal Attendant (for whom payment of full fee would present a hardship) .... $45.
Family (group rate) .... $130.
Lifetime Member: .... $1000.

All dues are $15 higher for members outside the U.S. & Canada.

If you would like to charge your membership, please fill in the necessary information:

( ) MASTERCARD ( ) VISA ( ) DISCOVER

Card Number ______________________

Expiration Date ______________________

Signature ______________________

( ) I would like to arrange to spread my payments out. Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

How did you learn of TASH: ______________________

____

What, in particular, inspired you to join: ______________________

____

What other disability organizations do you belong to: ______

Referred by: ______________________

If you are applying for a student membership, please provide the following information:

Department ______________________

College/University ______________________

Student I.D. Number ______________________

Anticipated year of completion ______________________

( ) Please check here if you would like us to send information about your local TASH Chapter.

Please make check payable to: **TASH**
Address: **29 W. Susquehanna Avenue**
Suite 210
Baltimore MD 21204
Telephone: **410/828-8274 Fax: 410/828-6706**

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Address Correction Requested

APRIL 1997

TASH

Newsletter

VOLUME 23 **ISSUE NUMBER 5** **MAY 1997**

Also in this issue:
Amending IDEA, Special Olympics and Tools for Change

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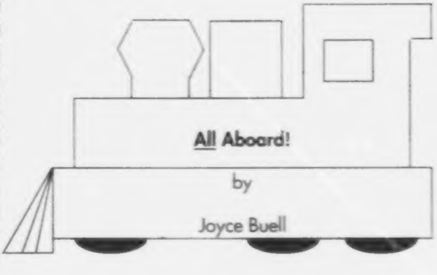
Joyce Buell will be a
Keynote speaker at the
1997 TASH annual conference
in December.



All Aboard!

by

Joyce Buell

He held a ticket in his hand,
Like everybody else.
He stood in line with all the others,
Waiting . . .
The train of life arrived; he cheered
Like everybody else.
Doors opened to embrace their upturned
Faces.

When his turn came to board the train,
Like everybody else,
The ticket-taker shook his head
And said:
"You won't be going half as far
As everybody else.
It's best for you to wait here; please be
Patient."

Train windows gave him one last glimpse
Of everybody else.
He winced at the conductor's:
"All Aboard!"
The train of life rolled down the tracks
With everybody else,
But left him standing, lonely at the
Station.

Sometimes he'd see the train as he looked
Out through the bus window—
Lights'd flash, the driver'd brake, the gate'd
Come down.
The train of life would whiz right past them
At the railroad crossing . . .
Disappearing down the tracks
Of time.

Then suddenly, from nowhere, came
A little yellow bus.
The driver took his hand, said: "Come
With me."
"But, sir, I'm waiting for the train,
Like everybody else."
The driver said, "You need our help to finish
Packing."

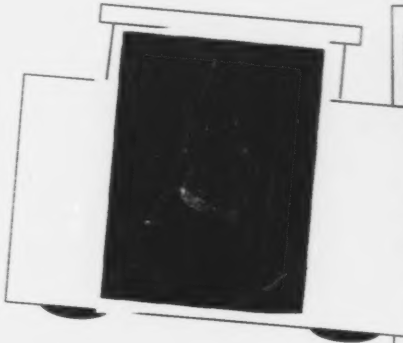
The driver'd say, "I promise you a
Train ride, when you're ready."
He'd pack this promise in his suitcase with
The rest.
His ticket read: JUST ONCE AROUND
Like everybody else's.
His suitcase filled with promises grew
Heavy . . .

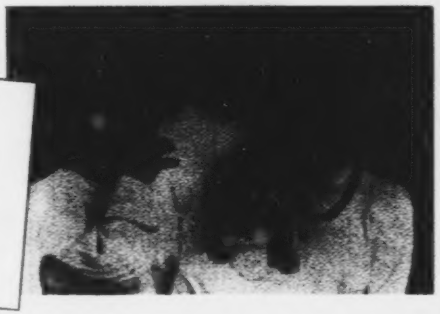
One day he fell asleep aboard
The little yellow bus.
He dreamed an angel whispered in
His ear:
"A little yellow bus ride can't
Prepare you for the train;
Getting ready will not happen
Sitting here.

'Cause ready is, as ready does,
As everyone should know.
You're as ready as you're ever going
To be.
A suitcase filled with promises
Does you no good at all;
It's the journey, not the packing—that's
The key."

In spite of angry
Protests from the driver,
The angel led him off the bus, onto
The train.
They left behind that suitcase filled with
Reams of Jabberwocky;
What he really needs, he'll learn along
The way

The ride is sometimes bumpy, and
The tunnels, very dark,
As the train of the life rolls swiftly down
The tracks.
But he'd rather feel the ups and downs
With everybody else—
Life's for living, not for looking at
Through glass. ©1992

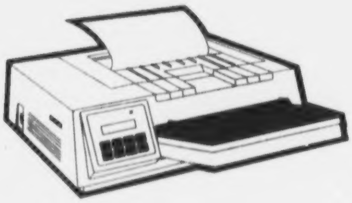




L-R: Donnie, Don, Maggie and Joyce Buell

Thanks for the February 1997 *Newsletter*, "A Good IDEA." After reading Frequently Asked Questions about Part B of IDEA, I finally got it! The questions and answers were not condescending and, yet, they were extremely clear!

Gayle Haffner, Administrative Law Judge
Baltimore (County), Maryland



As I read the February TASH *Newsletter* devoted to IDEA, I could not help but reflect how it was for myself and my dear parents almost fifty years ago. Then, there was only one public school for the "handicapped" in Toledo, Ohio (my hometown).

Back in the late '40s and early '50s, the most 'popular handicap' was polio. We 'severely CP (cerebral palsy) quads' were discreetly advised to have 'bedside' teachers, because the school was not 'equipped' to handle 'severely CP quads.'

I must admit that for four years, I received an excellent education at home and, I now realize in retrospect, this gave me a good foundation for things to come. But something very important was missing.

As I was entering my fifth year of home teaching, my sister started school. After a month of watching little sister go off to school every day, I revolted. My Mom and teacher broke down in tears, for all knew what uncertainty lay ahead. Through their tears, they both asked, "why?". My only answer was that I wanted to be with other kids.

... I guess the only purpose of this lengthy message is not to go back to the 'dark ages' of those years of my youth.

IDEA Works! Don't mess with it!

Dennis Toomey
Covina, California

TASH welcomes Letters to the Editor. If you would like to render your opinion on an issue you've seen addressed in the *Newsletter*, send your correspondence to: Priscilla Newton, TASH *Newsletter*, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204. You can also fax or e-mail your letter: (410) 828-6706 or pnewton@tash.org Letters (or excerpts) may be reprinted in upcoming issues of the *Newsletter* as space allows.

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Observing Responsiveness Among Infants with Multiple Disabilities .... Page 24

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TASH (The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

Building communities in which no one is segregated and everyone belongs;

Forging new alliances that embrace diversity;

Advocating for opportunities and rights;

Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

Supporting progressive legislation and litigation; and,

Promoting excellence in services.

EDITOR'S NOTES

Although the Call for Presentations for the 1997 Annual TASH Conference has passed, and the Awards Application has already appeared in an earlier *Newsletter*, when you see the Conference Registration Form for the first time, you know it really is time to start making your plans for Boston!

The registration form, along with information on travel and hotel reservations, is provided extra early this year so you can make your arrangements right away. Think of the peace of mind you'll get knowing that your registration has been sent in, and your travel and hotel have already been booked, assuring both favorable air fares and ample space at the conference hotel.

Information on the conference, along with the registration form, starts on page 28. You'll also find the Awards Application - which can be used to submit an application for the Hayden Fellowship, Collaboration, Media, or Positive Approaches Awards - on pages 21-23.

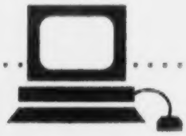
Feature articles in this month's *Newsletter* include the story of one parent's personal involvement in the battle to amend IDEA (page 6). David Hingsburger's article, beginning on page 10, also gives a personal perspective on how his view of the Special Olympics was broadened once he actually witnessed the games.

Marsha Forest and Jack Pearpoint share creative change tools with readers (page 13), and issue an invitation for others to share effective tools they've found or developed. In the way of other resources, we've put together a brief list of web sites which may be of interest to parents (page 16), and beginning on page 24, Guess, Roberts, Holvoet and Rues provide an overview of a joint research survey which observed the responsiveness of infants with multiple disabilities.

Also on the conference front, mark your calendars for the community-building workshop co-sponsored by TASH and the Center on Human Policy. With faculty to include John O'Brien and Connie Lyle O'Brien, Steve Taylor, Michael Kennedy, Bonnie Schoultz, and many others, this is one dynamic workshop you won't want to miss! Details, along with the registration form, can be found on pages 26-27.

Priscilla Newton, *Newsletter* Editor

WHOM DO I CONTACT??



- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on the conference, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For information on governmental affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:mroth@tash.org
- **For information on membership, permission and reprints, newsletter advertising, or publication/video sales, call:** Priscilla Newton, Director of Member Services, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the newsletter or to make a submission, call:** Priscilla Newton at (410) 828-TASH, Ext. 102.
- **Don't forget to visit TASH's web site at http://www.tash.org**
- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230, e-mail: lgoetz@sfsu.edu

The TASH Newsletter is available on audiocassette for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail: pnewton@tash.org.

FROM THE EXECUTIVE DIRECTOR

BY NANCY WEISS

Several issues ago, I wrote an article seeking members' input on the TASH name. I explained that many members had expressed concern about our name; some people had even told us that their reasons for not joining or re-joining TASH had to do with their discomfort around the name.

The Board has discussed a name change a number of times. It was clear to them that, in addition to containing language that is somewhat archaic, the name may imply misinformation about who falls, or does not fall, within the circle of our advocacy and activities. There was also, however, understandable concern about giving up the TASH acronym, which is so widely recognized.

A number of names have been suggested over the last couple of years. Some maintained the TASH acronym, others didn't. Names that have been proposed include:

The **A**ssociation (or **A**lliance) for **S**ocial Justice and **H**uman Rights
The **A**ssociation for the **S**upport of **H**uman Rights
Toward **A**dvocacy, **S**elf-Advocacy and **H**uman Rights
International **D**isability **E**quity **A**lliance (IDEA)
Disability **A**dvocacy **I**nternational
The **D**isability **A**ction **C**oalition
The **D**isability **A**dvocacy **W**orldwide **N**etwork (DAWN)
The **D**isability **A**ction **N**etwork
The **A**ssociation for **D**isability **A**dvocacy

In the article a few months ago, we asked for members' opinions. Specifically, we asked:

1. Do you feel the term "disability" should be included in the name to make clear our areas of concern, or is it better to leave it open?

2. Do you think it is important to maintain the well-recognized acronym, or should we undertake the effort (and expense!) to change to something new?

3. Do you like any of the names above, any variations on these, or have a suggestion for a new name?

We got a great number of responses (all via e-mail, interestingly enough). Some people thought we should "stick to our knitting" and avoid a name that communicates that we are trying to become all things to all people. Some felt it was important to maintain the acronym; others viewed a name change as being worth the risk. Here are some excerpts:

I feel that it is time for a name change. Students and colleagues whom I introduce to TASH for the first time want to know what TASH stands for. I tell them what the acronym stands for technically ... (then) I describe us as an organization of people who support the principles of inclusive education and inclusive community, and who work as advocates in tearing down cultural barriers that prevent people called disabled or handicapped from being seen as valued members of our society. I wish there were a name that could include the term disability, but not make it sound like a term of exclusion. Like, "working to eradicate disabling images of differences in ability." I like the recognizability of "TASH," and even revel in being known as one of those radical inclusionists!

— Liz Altieri, Virginia

I think the word "disability" should be in the organization's name. I've had this discussion with many consumer advocates over the years, and understand the aversion to having the "label" in the name. But I stand by my opinion that as long as public dollars for supports are categorized and distributed in accordance with such labels, the label is needed in the name. The TASH acronym, like that of the Arc, would appear to me to be important to retain because it is well known. To change it would require an extensive and costly campaign to acquaint the disability community with the new acronym. "The Association for the Support of Human Rights," has the attraction of retaining the acronym, as does "The Alliance for Social Justice and Human Rights," which I like even better. However, neither provides the outside world with an understanding of just who the organization is most concerned with in its fight for social justice or human rights. For me, the crux of the matter (is) what do members with disabilities find advantageous and/or repugnant in the current name, and what would they propose as an alternative.

— Mark Wurzbacher, Maryland

In the past, some groups attempted to become all things to all people, and this ultimately led to some organizations' downfall. Our organization is an advocacy group for people with disabilities ... it is our niche. If the organization does change its name, the new name should include advocacy and disability. My concern is ... people tying our mission to world peace, social justice, or anything else besides the advocacy for persons with disabilities. Please stay the course. Do not follow what I feel is a vocal minority and become an organization with too wide a mission. I like the idea of maintaining the acronym with a tag-line like the one you currently use, "Disability Advocacy Worldwide." I like that better than a full scale name change to some new-age, feel good abstract concept that may cost us future members and, possibly, our place in the world of assisting persons with disabilities.

— Tom Sinclair, Iowa

I have been a member of TASH since 1983, and think we are ready for a name change. I feel the term "disability" should remain in the name to clarify what our area of advocacy is. I like the names: Disability Action Coalition and The Association for Disability Advocacy.

— Kenna Colley, Virginia

I like "The Disability Action Coalition" or "The Disability Advocacy Worldwide Network." They sound like they cover a broader constituency. Thanks for asking for input, I have been bothered by the name.

— Debbie Bruns, Illinois

The TASH recognition is important, but we need to update to more appropriate and people first language. I like "The Alliance for Social Justice and Human Rights."

— Rita Skiles, Nebraska

The discussion is not closed! Have some thoughts to add? Send us a fax, c/o Nancy Weiss at: 410-828-6706 or send an e-mail to: nweiss@tash.org

A Parent's Thoughts on Amending IDEA in the 105th Congress

BY DEB KUNZ

It began with a phone call in early March or April, 1996. I watched as the 104th Congress proposed bills which would effectively destroy our children's rights, and gut hard-won procedural safeguards that we parents and other civil rights proponents had fought to include in the Individuals with Disabilities Education Act. All of this bureaucratic, policy-making activity occurred seemingly without strong opposition from disability advocacy groups in Washington, D.C. At best, people around the country received mixed messages from these groups, who made such statements as, "This is the best we're going to get, and we need to accept that and show our support." or, "If we don't come to the table, we don't get to play the game!"

Why would families want to play a game which places families' and children's rights at risk? Why would we want to support a potentially destructive bill? Families and advocates in Illinois (where I live) wanted to see positive changes, but not at the expense of giving up the basic tenets which are so important to us all.

In my frustration, I turned to TASH. I am a former board member of IL-TASH (Illinois TASH Chapter), and I know TASH to be the premier advocacy organization for people with disabilities. I talked with Marcie Roth, Director of Governmental Affairs, on that day last spring and we began our mission. Marcie set up a conference call with Frank Laski, Mark Partin, and Kathy Boundy of TASH's Governmental Relations Operating Committee, Rene Leininger and Kerry Flynn from the Illinois Planning Council on Developmental Disabilities, Ruth Henning and John Donnelly from IL-TASH, and myself.

We began our united effort that day, and together we composed an Action Alert that was short, simple, and to the point, educating people about IDEA and the proposed amendments. We sent it out, gave people the information we had, and we asked people to speak out and make their voices heard. Collectively, we were able to stop the proposed bills, which included cessation of education services for some students, from passing in the 104th Congress.

There was little time to rest, however. In early January, the 105th Congress submitted bills which were nearly identical to those we rejected only a few weeks earlier. Parents and advocates across the country were horrified and outraged. As a result, Senator Jim Jeffords (R-Vt) and Representative William Goodling (R-Pa) held a meeting in February to announce a bipartisan, bicameral effort to reauthorize IDEA. The Congressmen recognized the efforts of the people in communities across the country, whose stand had halted the reauthorization process in the 104th Congress.

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> "Why would families want to play a game which places families' and children's rights at risk? Why would we want to support a potentially destructive bill?"

A PARENT'S THOUGHTS

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The two men devised a process encouraging the participation of Washington-based disability advocacy groups, and family, advocacy and general education groups from around the country. Timelines were set for four weeks, coinciding with the Congressional spring break. Attendees at the meeting were told that if we couldn't reach consensus by then, the process would revert to the "regular legislative process," which aides assured us we wouldn't want.

We were also told that this meeting was "off the record," and we were advised not to talk with the press. The meetings had been organized in a town meeting format. People lined up, spoke to their issues, which were then recorded on a flip chart, and that was about it. There was very little comment from the panel, headed by David Hoppe, Senator Trent Lott's Chief of Staff. Other panel members included staff of key Congressional committee members, as well as Judy Heumann, Assistant Secretary of OSERS (Office of Special Education and Rehabilitative Services) and Tom Hehir, Director of OSEP (U.S. Department of Education, Office of Special Education Programs).

As I write this article, Congress has reconvened from its spring break. There have been more meetings than originally scheduled but, still, we have not seen a bill. Around April 16th, principles for draft bill language were agreed on by members of the Senate and House committees. Hopefully, in the next day or two, advocates and families will receive a copy.

In closing, I gratefully acknowledge the hard work of people whom I have had the privilege to meet during this process. This endeavor has forged new friendships – bonds strengthened by our common goals. Together, we have worked, worried, rallied, shared our pain, and kept the faith over the last year or so.

Some of my thoughts, concerns, questions, and perspectives on the people, the process, and the amendments themselves:

- It's great that families across the country were asked to attend. It's clear that lawmakers understand that our voices could not be adequately represented by the lobbyists and Washington-based advocates.
- These meetings are unprecedented. They are a recognition of, and a respect for, the power of families and advocates in communities across this country.
- Lawmakers sometimes need a reminder that they are public servants. They work for us; we are not subservient to them.
- Some people seem, for whatever reason, to have lost sight of our history, and the dangers that compromise can bring when it erodes our basic civil rights.
- Many thanks to Tom Gilhool, of the Public Interest Law Center of Philadelphia, for his efforts at keeping the history of the efforts to educate all children with disabilities alive.
- David Hoppe deserves credit for listening to all perspectives, including students, and acting on suggestions that the panel make site visits to schools.
- Where is the process whereby those who purport to represent our concerns in Washington are held accountable?
- It has been amazing to see the coalition to preserve IDEA build! The most effective way to counter the big money lobby is with great numbers of people. The united effort to stop the destruction of our rights has grown like wildfire, and brought together a very diverse group of families, advocates, and professionals.
- The IDEA is 22 years old; it is not archaic. It has never been fully enforced or implemented. Our Constitution is over 200 years old, but no one says that because times have changed since the 1700s, maybe we need to do a wholesale rewrite. The Constitution is altered carefully, only in rare instances, and then by adding amendments. I guess this comparison gets to the heart of the subject. Families and advocates see IDEA as our "Constitution for the Education of ALL Children with Disabilities." We cannot fathom a need for a rewrite. Why do we need a rewrite now? Part B has already been permanently authorized.
- Could it be that since families are now winning major inclusion court cases under current law, that the anti-inclusion forces are determined to gut and change the law?
- Are people inside the beltway so involved in the process that they don't realize what they are giving away?

I don't have any answers. I only have more questions.

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A PARENT'S THOUGHTS

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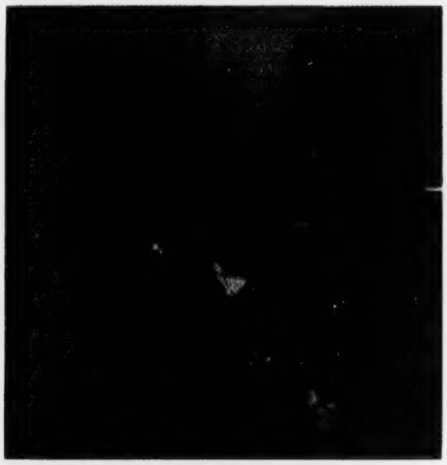

L to R: Art, Deb and Andy Kunz

The following people are heroes to those of us who support equality and justice for ALL: Rene Leininger, Kerry Flynn, Bill Kienzle, Tom Gilhool, Marcie Roth, Kathy Boundy, Frank Murphy, Kathleen Marafino, Jamie Ruppman, Lisa Baach, Matt Cohen, Frank Laski, Barbara and Wayne Dyer, Martha Ziegler, Liz Healey, Maureen Hollowell, Tom Shade, Paula Goldberg, Margaret Burley, and Sue Pratt.

I am eternally thankful to all of you for the support you've been to me, my family, and families all over the country.

Deb Kunz, along with her husband Art, and son Andy, battled to support Andy's right to communicate using facilitated communication, and to obtain an inclusive education for him in his home high school. Deb is the Executive Director of Family T.I.E.S. Network, a not-for-profit parent and individuals with disabilities organization based in Springfield, Illinois. For more information on Family T.I.E.S. Network and its work, call 800-865-7842.

TASH gratefully acknowledges the generosity of Kraig Scheyer of Redondo Beach, California, who designated TASH as a recipient for a payroll deduction contribution.

Thanks, Kraig!

If you are interested in making a contribution to TASH through a payroll deduction, consult the Payroll Office at your place of employment. Contributions can also be made directly to the organization. TASH is a 501(c)(3) organization.

URGENT!! URGENT!!

As this issue of the TASH Newsletter goes to press, we've received late-breaking news from inside the Beltway:

Despite the unified voices of parents and advocates across the country calling for enforcement, rather than a wholesale rewrite of the current Individuals With Disabilities Education Act, both the U.S. House of Representatives and the Senate voted in favor of the Individuals With Disabilities Education Amendments of 1997.

Specific information on the contents of the IDEA Amendments can be found at TASH's web site, http://www.tash.org

Also, look for a complete analysis of the new law, and how it will affect children and their families, in the next TASH Newsletter.

"Goodling IDEA Rewrite Should Move to House Floor by Recess"

(FROM THE *CONGRESSIONAL QUARTERLY MONITOR*, APRIL 17, 1997)

IDEA

Rep. Bill Goodling, R-Pa, chairman of the Education and the Workforce Committee, says that "negotiations to reauthorize programs to provide education to the disabled are 'in pretty good shape'," and he hopes to get the bill to the House floor before the Memorial Day recess.

Meeting behind closed doors, House and Senate staff from both parties have been drafting a compromise bill to renew the Individuals with Disabilities Education Act (IDEA), which authorizes federal aid for children with disabilities. Last year's rewrite fell apart over several issues, including funding formulas and how much leeway schools should have in disciplining disabled children with severely challenging behaviors.

Goodling said that compromises have been reached on both issues and that staffers will brief relevant interest groups in the next couple of weeks. While he would not discuss specifics, he said language on the discipline issue won't "totally please the educators, because to do so would be to displease disability groups. So, probably both sides will be a little bit displeased."

At issue in the funding question was whether to base it on the number of children with disabilities in an area, or on the total school-age population.

Goodling said negotiators, including Clinton administration officials, have tried to "make sure we don't over-identify [disabled children], and make sure we serve those most in need."

He predicted the compromise is something "that we can agree on here in the House in a bipartisan fashion."

If you have questions or would like additional information on the status of the bill, contact TASH's Director of Governmental Affairs, Marcie Roth, at: (410) 828-8274, ext. 103 (voice); (410) 828-6706 (fax); or mroth@tash.org (e-mail)

Announcing

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A creative and dynamic one week experience, facilitated by leading activists in building inclusive and diverse communities, schools, and workplaces. Join our international faculty in building a unique Learning Marketplace. Come and be part of an innovative and creative approach to learning. Practice new and colorful tools to take us into the year 2000. We believe "Together We're Better!"

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Dave Hingsburger's 'Hot Fudge Sunday'

BY DAVE HINGSBURGER

Dave Hingsburger teaches, lectures, and makes videos and books from the headquarters of Diverse City Press in Montreal. He is the author of Just Say Know! And Behavior Self. Dave is one of the scheduled keynote presenters at the 1997 TASH Annual Conference in Boston.

The television lights were hot. Never having done live television, been on a studio set, or worn make-up in the middle of the day, I was terrified. An odd week began with a call from CBC's *Sunday Morning Live* and ended under lights. I was to comment on media coverage of the Special Olympics (SO) World Games. Then, I was to debate a sports reporter, who contended that the SO was "cute," but not "sport." Martin Fudge, an Olympic champion, rounded out the panel. Strong, articulate and passionate, he is everything that athletes should be but aren't, anymore.

Approaching the task seriously, I read articles and watched television stories. I set three criteria for judging reports: did they portray the competitors as *athletes, as adults, as able*? The week began with "on the street" reports by a chipper newswoman, who pointed to Olympians walking by and said, "If you see a group in brightly colored jackets, make sure you say 'Hi' or give them a welcoming hug." Cleaning projectile vomit off my television, I almost quit. But, sensing the opportunity to learn something, I pressed on.

On Thursday, I went to the figure skating. Something interesting was happening. A growing awareness was creeping into news reports. There was even an occasional bit of grudging respect for the athletes as athletes. Parking in the lot outside the arena, I felt ambivalent about attending. For years, I had heard nothing but negative things about Special Olympics. Early on in training, I was made to chant words that now ricocheted in my head, *Congregate, Segregate, Persecute, Destroy*.

Entering the arena, I remembered the respected professional who was horrified that I would attend. "Special Olympics is just wrong. It's an oppressive mechanism built on segregation." Her outburst took me aback. She said she had never attended an SO event, and didn't need to; "segregated activities are just wrong."

Taking a tiny seat made for the butt of a lithe-bodied child, I groaned in pain. A half hour was all I'd need to get the flavor of the event. I stayed four hours. I haven't had so much fun at a sporting event since Dale Taylor's pants split during soccer practice, but that's another story. I laughed, I cried, I fumed at judges' decisions, I cheered for favorites, I ate arena popcorn. I didn't observe, I plowed in.

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Dave Hingsburger

> *"I wonder if the ideologues who would determine the lives that people with disabilities live, went to the games. . . . I wonder if those who think that people with disabilities should be disallowed from sport, social contacts, and media coverage would think the same if they stood in an arena filled to the brim with pride."*

HOT FUDGE SUNDAY

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On the ice were people with disabilities with cool hair cuts, wearing great costumes, skating to music. In the stands were the throngs. So who was the audience? I asked one of the ushers and she said, "The arena has been full since we started this morning. A lot of the kids are from schools. Many folks are arena regulars, but even more are people who saw the sign outside announcing figure skating. They came in not knowing that it was the SO. And you know what? They stayed. I was so wrong. I expected people to be disappointed that it wasn't 'real' figure skating and leave."

The media, however, had difficulty. Seven media crews arrived and struggled for a story. They interviewed organizers, volunteers, and members of the audience. They didn't realize that the story was on the ice. And, boy, was it! The competitors were serious. Not one of them looked at the audience, played to the cheers or forgot their program. I don't know why I expected less. I admit to my own prejudice. I expected a lot of cutesy behavior and a patronizing audience. I was completely wrong.

Those opposing Special Olympics need to attend the games and see competitive concentration. One man took the ice and when the music began, he signaled for it to stop. He bowed his head, crossed himself, prayed, and then looked up and signaled for the music to start. After he finished, before he took his bows, he repeated the ritual. A woman behind me whispered to her friend, "I didn't know they prayed." As waves of people came and left, I began listening to observers' remarks. This would give an impression about the effect that the games had on the public.

Two rows back, a mother talked to her child, telling her that if she worked hard at her skating, she, too, could compete. The little girl asked if she could wear a costume and go out in front of everyone. Mother assured her that with practice, she could. I turned expecting to see a mom and child with Downs. But this was a typical mother, talking to a typical child, and using a person with a disability as an example!

Saturday, I visited an elderly woman from my congregation recovering from a stroke. She said excitedly about SO, "Isn't it tremendous what's happening? In Magog, when I was a girl, there was a child with a disability who lived down the street. She was taken out every evening after dark for exercise. No one ever saw the child in the light. Now, people with disabilities are on television skiing and skating!"

At the closing ceremonies, Martin Fudge walked out on stage. I had read about him in the *Globe*, the *Mail*, and the *Toronto Sun*. He strode to the microphone. He was awesome and in total control. Near the end of the speech, his voice rose with strength and conviction as he shouted, "We have proved to the world that we are athletes." This, to me, was the defining moment of the Olympics.

Arriving at the studio, I went into make-up. Martin was just finishing and, while waiting to go in, we chatted. We joked around, and I told him that he and I were bound to be friends because I was fat and his last name was candy. We both laughed and the tension broke.

He told me how much SO had meant to him, and how he loved representing Canada. He recounted stories of professionals who had told his parents that he would be a vegetable. He shocked me by telling me that he had had a great deal of difficulty with speech. The man who had brought the house down the night before, had once been told that he'd never learn to talk properly. I suggested sending a video of the ceremonies to his speech therapist. He smiled at the idea. We were then called to the set.

In ten minutes, Martin discussed his love of sport, the sports guy made points about what "sport" is and isn't, and I got in a couple of remarks about media, disability, and the politics of respect. The time quickly disappeared. Martin and I then shook hands, and he headed home to Nova Scotia, while I headed home to Quebec.

Upon arrival, I received a disturbing voice mail, "I have lost all respect for you. You should have talked about how people with disabilities shouldn't be congregated. You were given an opportunity to attack segregation, and you sold out. I have never been more disappointed in someone than I am right now." No name, no number, no courage. So, there you have it. I sold out to the CBC for a *Sunday Morning Live* coffee mug.

I wonder if the ideologues who would determine the lives that people with disabilities live, went to the games. I wonder if those who are philosophically pure would have the courage to tell Martin Fudge that he is perpetuating oppression. I wonder if those who think that people with disabilities should be disallowed from sport, social contacts, and media coverage would think the same if they stood in an arena filled to the brim with pride.

Yes, we have far to go. But it has always been my contention that without pride, there can be no effective political movement. The Special Olympics showed me that it is possible to turn 2,000 people with disabilities into athletes. To me, it is only a short run from pride in sport to pride in self. From pride in self, it is only a jog to pride in purpose. But it is we in human services who have dropped the torch. SO shows that pride is possible. We haven't yet understood the possibilities of pride.

And, to Martin, pride was the point, and medals were just the cherry on top of his Hot Fudge Sunday!

As seen in *Community Living News* – Spring 1997, Vol. 15, No. 1. Reprinted with permission of the B.C. A[illegible] for Community Living and the author.

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Share Your Life.
Share Your Decision.(sm)

Today, the fate of more than 51,000 Americans hangs in the balance as they wait for the gift of life – organ donation.

These individuals are on a national waiting list to receive life-sustaining organs. Unfortunately, close to 4,000 will die this year, or an average of nine per day, because suitable organs are not available.

The need for organ donation has become a national health care emergency. In 1996, only an estimated 5,400 Americans were organ donors. This small number represents only one-third of potential donors in this country.

Many people believe that signing organ donor cards, or indicating their desire to become organ donors on their driver's licenses, is sufficient. However, this alone will not guarantee that an individual will actually become a donor. Physicians usually seek consent from next-of-kin before going forward with the donation. If surviving family members are unsure about their loved one's wishes, they often will refuse the option of organ donation. Thus, talking with your family about your desire to be a donor is vitally important.

If you or your family members wish to become organ donors, discuss it, and make sure your wishes are known to each other.

If you haven't told your family you're an organ and tissue donor,

you're not.

To be an organ and tissue donor, even if you've signed something, you must tell your family *now* so they can carry out your decision later. For a free brochure on how to talk to your family, call **1-800-355-SHARE.**

Organ & Tissue
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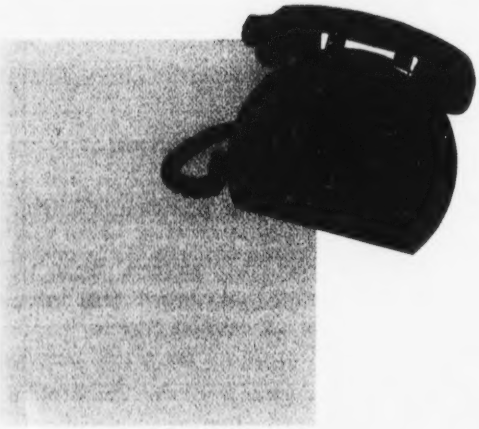
PRACTICAL AND USEFUL TOOLS FOR CHANGE



BY MARSHA FOREST AND JACK PEARPOINT

Beginning with this issue, a new semi-regular feature of the TASH *Newsletter* will be an article called "Practical & Useful Tools for Change." To move into the new era of "inclusion," we need to use new and creative tools. We can no longer do **MOTS** - 'more of the same thing.' If you have a creative tool for change you'd like to share, send it to us and we'll consider publishing the tool in a future article.

This article will be an example of NO MOTS. When we discussed the term MOTS with aboriginal health care workers and head start educators in Winnipeg, they told us the word MOTS in the Cree language means "no!" Interesting. No more of the same thing. We can't get to the future by using old ways of working.

The Four Questions

The first tool will be The Four Questions, designed by us, for individuals, families, and organizations to engage in constant improvement.

1. What are we doing well right now?
2. What could we be doing better?
3. What could we be doing differently?
4. What can we do now (within 48 hours) to start doing things better and/or differently?

We have designed The Four Questions exercise to help families, groups and organizations to get out of the trap of negative thinking. We hear so many people asking, "*What are we doing wrong?*" This is a fundamental error. "*What's wrong?*" is the wrong question, and sets the wrong answer in motion.

For example: An organization we work with truly wanted to do better. They kept asking the people they worked with to tell them what was wrong, so they could improve. But the people told them everything was really OK. Everyone knew it wasn't. They were stuck. And asking the same questions louder did not achieve a breakthrough.

There were good reasons they couldn't get the information they were seeking. First, the "consumers of their service" didn't want to hurt anyone's feelings. Their lives were so much better than in the past, they didn't want to complain. They knew some things weren't right. The organization also knew there were problems.

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TOOLS FOR CHANGE

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We suggested they ask a new set of questions:

- The first question is: "What are we doing well right now?"

This question positions everyone to succeed. We didn't phrase it, "What are we doing really great?" That creates a different tension. Simply ask, "What's OK?"

So they asked. People suddenly gave clear and plentiful feedback. Some examples: *"The staff are really nice people, they work really hard." "We like being in the community." "We like certain individuals." "We like going to the new mall." "Our neighbors are great."*

- The second question is: "What can we do better?"

This question got to the heart of the matter. People had already given some positive information, so they could feel free to tell what could be done better.
Here are some examples: *"The food could be more spicy and better." "I want to choose my own roommates." "It could be better if I could help hire my own attendants." "I need better transportation so I can get into town more." "Fix it so we can go more places."*

- The third question takes a new twist and asks, "What could we do differently?"

Now we get some real creativity. Examples include: *"We could start the project all over again." "We could all go away for two days and really talk about what needs to be done." "We could pay people more and make their hours flexible." "We could rent or lease a car, so we can get places and make sure all the staff drive." "If a staff person doesn't drive, we could get someone to donate driving lessons or teach anyone who wants to learn to drive."*

- The fourth question, given that we know people need to do something within 48 hours if they are going to start any process of change, we should ask is "What can we do now (within 48 hours) that can help us get started on making ourselves both better and different?"

Examples include: *"We can set a date for the retreat." "We can stop and really think about what we are doing." "We can make a list of what we do well, and put it on the wall so we aren't always focusing on the negative." "We can get Jane to driving school tomorrow, as she's great, but she can't drive."*

Now, use your own family as an example for a few minutes. We urge people to sit down, with one person taking notes, using words and/or graphics. You could use a tape recorder, if you want. Do what it takes. If someone doesn't speak with words, use any means possible to get them communicating.

Give each person adequate time to answer, and listen to what they have to say. Encourage each person to give at least three responses to each question and, certainly, more are welcome.

Here's an example of how one family used this tool. This was a family of 5: father, mother, and three children - ages 12 to 18. One child uses facilitated communication to speak, and he said plenty.

What are we doing OK?

- *We like each other.*
- *We try to talk to each other.*
- *Mom cooks good.*
- *Dad works a lot, so we can have toys.*
- *We care for one another*
- *We watch television quietly.*
- *We clean up (sometimes!).*
- *We talk to grandma every week.*

What could we do better?

- *Watch television less.*
- *Talk to each other more.*
- *Come to dinner when mom calls.*
- *Not talk to our friends on the phone so much.*
- *Not tease each other.*
- *Tell each other good stuff.*
- *Not argue so much.*

What could we do differently?

- *Turn off the television at 8 P.M. and talk together for half an hour at least four times a week.*
- *Turn off the phone at dinner so we can talk to one another.*
- *Thank Mom when she makes a good dinner.*
- *Ask Dad to be home for dinner at least twice a week - and on time!*

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TOOLS FOR CHANGE

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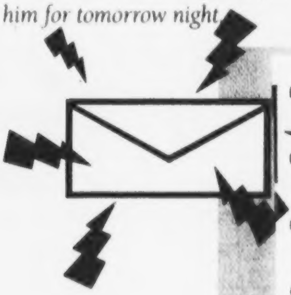
What can we do right now?

- *Tonight, we can turn off the television and talk.*
- *We can do this four question exercise once a week. Let's schedule it for every Wednesday night.*
- *Dad can come home for dinner tonight.*
- *Let's call him now, and if he can't come tonight, we'll get him for tomorrow night.*

The feedback from the family was great. They said the exercise helped focus them. It acknowledged their good points, which they often forgot. It gave them realistic, attainable challenges. It gave them an opportunity (in about 15 minutes) to think about what they really needed to change and how to get started. It enabled them to put thoughts into action. It got them unstuck. They said it started them on a manageable plan of action to communicate with one another, as that seemed to be the main problem (as it is with so many families).

These are 4 powerful questions. Let's review:



Question One (gets you out of the negative): "What are we doing now that's OK?"

Question Two (leads to constant improvement): "What can we do better?"

Question Three (leads to creativity and lateral thinking): "What can we do differently?"

Question Four (leads to first steps and doable action): "What can we do NOW (or within 48 hours)?"

Whether by yourself, in twos, in teams, or in larger groups, this is a usable and doable exercise to start change. We use it ourselves. You can do it with children and adults. You can ask children, "What did we do OK today? What can we do better? What can we do differently? What are we going to actually do tomorrow?"

The Four Questions are not about "trying" to change. They are about actually taking small, possible steps to do something to really change. Until small steps are actually taken, families or organizations are never going to get to the really big stuff. Changing the world only comes from doing something real today. One step at a time is truly the only way to go. Step by step gets you to the top of the mountain.

Don't try it. Do it and let us know what happens.

Want to share the results of your 4-step exercise or a creative tool for change? Contact Marsha and Jack c/o
Inclusion Press International, 24 Thome Cres.,
Toronto, Ontario M6H 2S5 CANADA
Telephone (416) 658-5363
Fax (416) 658-5067
Visit our web page: http://Inclusion.com [New Stuff]
E-mail: 74640.1124@Compuserve.com

On-Line Resources!!!

The June 1996 TASH *Newsletter* featured an article on disability-related web sites and other technology-related information. Many readers have commented on the usefulness of this resource and, as we collect additional sites, we'll pass them on.

This list consists of several sites which should be of particular interest to parents. If you have located a site on the Internet that provides resource information, offers expertise in any area which may be of interest to parents, self-advocates, professionals and/or paraprofessionals working in disability-related fields, or updates on legislative activity which may be of interest to our members and readers, please feel free to share it with us! E-mail the location to us at pnewton@tash.org.

See ya' in cyberspace!

Priscilla Newton

INTERNET RESOURCES

Worldwide Web Sites:

These web sites have disability-related information for parents:

http://www.chadd.org
Children and Adults with Attention Deficit Disorders

http://www.soe.uwm.edu/dec/dec.html
Division for Early Childhood of the Council for Exceptional Children

http://www.nas.com/downsyn/net1.html
Down Syndrome Home Pages

http://curry.edschool.virginia.edu/go/specialed/
Educational Resources Information Center (ERIC)

http://www.pacifier.com/~estiles/
Help For the Family with the Special Child

http://www.edc.org/FSC/NCIP
National Center to Improve Practice in Special Education Through Technology
(promotes the use of technology to enhance educational outcomes for students with disabilities)

http://www.aed.org/nichcy
The National Information Center for Children and Youth with Disabilities (NICHCY)

http://www.npnd.org
National Parent Network on Disabilities

http://www.php.com
Parents Helping Parents Web Site

http://www.chmc.org/departmt/sibsupp/default.html
Sibling Support Project

And, don't forget to visit TASH's web page at http://www.tash.org
Look for the1997 TASH Conference Registration Form at our web
site after May 15th, and register on-line!

Our web site also features links to other disability-related sites!

NOTE: TASH does not verify the technical accuracy nor any claims made in announcements on these services, nor does it warranty or guarantee any services or products that might be announced.

STANDING IN SUPPORT NOT CONTROL:

Training Toward Self-Reliance, Inc., Sacramento, CA

BY PAM WALKER

The purpose of Training Toward Self-Reliance, Inc. (TTSR) is "to increase opportunities for people with disabilities to lead good lives in places of their own, strengthen their communities, and enjoy a genuine sense of self-worth." TTSR was founded in 1982 to support people with developmental disabilities in the Sacramento area, within the 10-county Alta California Regional Center district.

Over time, TTSR staff have developed particular expertise in supporting adults with developmental disabilities to manage their own personal assistance services (PAS), supporting parents who themselves have disabilities, and supporting people with disabilities whose lives have been substantially affected by social problems associated with poverty, substance abuse, and interpersonal turmoil.

Based on the experiences of agency staff and the people they support, there are a number of lessons that can be drawn related to three critical service system issues: 1) lack of support for people with developmental disabilities to manage their own personal assistance services; 2) lack of support for parents with developmental disabilities to raise their children; and 3) service system control of people.

Personal Assistance Management Support

- *Personal assistance services and people with developmental disabilities.* TTSR staff support approximately 35 individuals with developmental disabilities in management of personal assistance services (PAS). Across the country, PAS have been utilized primarily by people with physical disabilities, but not developmental disabilities. In some instances, people with developmental disabilities would not be eligible for such services (e.g., if they were considered to be not "self-directing"). In other cases, people with developmental disabilities may receive such services, but with no support for management of these services; and, in some cases, people with developmental disabilities might receive PAS through an agency which takes control, thereby leaving the person with minimal

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STANDING IN SUPPORT, NOT CONTROL

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authority over who comes to work for them.

In California, people with developmental disabilities are eligible to receive PAS. However, often, there is no support available for them in the management of these services. TTSR has devoted significant effort to support people to manage their PAS. Following are some lessons based on their experience.

- *There is a significant degree of mistreatment of people with developmental disabilities who use PAS.* In the experience of staff at TTSR, mistreatment is a big issue. Support from TTSR has helped to reduce or eliminate some of the problems for the people they support. TTSR staff strongly feel that the risks should not be used as an excuse to take away autonomy and control but, rather, that people should receive support to deal with the problems.

> We have to work to understand how to sustain the autonomy aspect and still acknowledge that there are risks involved when you hire somebody to come into your home; that's really got to be confronted and managed, rather than just swept under the rug.

- *A broad range of supports should be offered to assist people with developmental disabilities to manage PAS.* The agency began involvement in PAS management support approximately 10 years ago. After a few years, they wrote a grant proposal in order to increase their understanding of key issues:

> We were trying to develop more capacity to head problems off—not just run after problems all the time. Also, we can not assume that any package of support is going to guarantee prevention of problems with assistants. What we were really trying to do is substantially reduce the odds of problems. And, it has really worked well.

TTSR now operates a course on PAS management at a local community college. In addition, staff assist people with such things as recruitment and supervision of assistants; development of back-up support plans; acquisition of technological adaptations; and the establishment of job descriptions and work schedules.

- *It is important to be prepared to offer support to people in negotiating relationships with assistants.* As one staff member described, "Friendships and complications do evolve. A lot of the people we see are so lonely, that fulfilling that loneliness is what they want in a person, that's one item on their job description." TTSR staff don't assume that friendships will evolve; they take the approach that this is an employment relationship. If, and when, a personal relationship does arise, however, they will assist the person in negotiating it, if desired.

- *TTSR has been very cautious and hesitant about becoming an employer of assistants.* Currently, money for employment of assistants for 10 individuals is funneled through TTSR. This arrangement—part of their supported living services—has enabled these individuals to receive a higher level of support than they would otherwise be able to obtain. But, on the whole, the agency has opted to co-manage assistants only in a small number of exceptional situations. According to the director,

> "We've been incredibly reluctant to get into the assistant hiring business, because it seems to change our relationship with the participant. The perspective really shifts when the assistant is your agency's employee. You have two responsibilities, and two obligations. You've got to keep the employee in mind, and that might be contrary to the preferences of the person who's using that assistant."

Support for Parents with Developmental Disabilities

Traditionally, within the service system there has been the assumption that people with developmental disabilities are incapable of parenting. Since 1986, TTSR staff have provided support to parents with disabilities. Currently, they support approximately 40 parents. Some of the lessons they have learned include the following:

- *When parents with developmental disabilities are charged with child abuse or neglect, this is primarily inadvertent rather than willful harm.* Staff feel that it is critically important to offer instruction in various aspects of child care and household management to parents with disabilities. They don't rely on a routine curriculum. Instead, they use various resource tools adapted to meet the needs of a specific family. They strive to identify and begin working with parents when they first learn they are expecting a child, rather than waiting until problems arise.

- *It is important to offer ongoing supports, rather than only time-limited supports.* In the past, the agency's services to parents were time-limited, tapering off over an 18-month period. Now, they offer the option of ongoing supports. This is based on their recognition that many families have difficulties that are not likely to be resolved through instruction. In addition, they feel that

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STANDING IN SUPPORT, NOT CONTROL

continued from page 18

societal factors—such as poverty, isolation, lack of available resources, domestic violence—create some situations which call for ongoing rather than time-limited support.

- *It is important to connect families with as many community resources as possible.* While TTSR staff assist families to obtain human service supports that they are eligible for, they place emphasis on developing and expanding people's connections to community resources. TTSR facilitators work exclusively in families' homes and in the community, rather than in a facility-based program. They support parents in a wide variety of ways, including: communication with school personnel and other professionals; participation in parent support groups; and facilitation of their children's participation in various recreational and other community programs.

Service System Control of People

Traditional service systems across the country have predominantly controlled people with developmental disabilities. This was particularly true with institutions, but has extended into community-based services and supports. TTSR is committed to not be involved in controlling people. This value, or commitment, drives the agency's decisions regarding support strategies.

- *The agency has avoided participating in the provision of "supported living services" that are characterized by control or supervision.* At the same time, they are committed to supporting people who need high levels of support. Along these lines, agency staff collaborate with other agencies, who share similar values, to support people who need intensive levels of support. In addition, they recognize the importance of combining both formal and informal, paid and nonpaid sources of support.

- *Agency staff strive to maintain each person-centered planning effort as a creative, unique, nonroutinized process.* Within a state context where person-centered planning is mandated, there is particular danger that it become a routinized process applied in haste across many individuals. TTSR has made an effort to ensure that this does not occur within the agency. They have used an outside consultant to assist with ideas and strategies, and they spend time together as a staff discussing and brainstorming creative, individualized responses, one person at a time.

- *Agency staff have made increased efforts to assist people to form and/or expand community connections and social networks, in order not to be primarily reliant on agency staff for social support.* They recognize their limitations, as part of the service system, in providing social support for people. While staff put significant effort into cultivating close relationships, these are still paid relationships, many of which end due to funding changes, staff turnover, and the like. Thus, one of the priorities for staff is to try to assist people to establish other, nonpaid, potentially long-term relationships.

Conclusion

A key strength of this agency is their values, and their commitment to making service decisions based on these values. Agency staff stand by people through many ups and downs in their lives. They do so based on an attitude that, "Failure is impossible" (Susan B. Anthony). They refuse to see these ups and downs as a failure on the person's part. They see success, for people they support, based on the perspective of the individual him- or herself; and not necessarily as attaining problem-free lives, but as acquiring new awarenesses, experiences, outlooks, competencies, and so forth. For staff themselves, success is doing their job well. Doing their job well is not about controlling people or forcing people to change. It is about building trusting relationships through which they can assist in enhancing people's quality of life, and it is about maintaining their commitment to treat people with full respect and dignity. In this way, staff at TTSR have been a critical source of influence and support in many people's lives.

Note: This article is based on a longer site visit report available from the Center on Human Policy. Appreciation is expressed to Charles Galloway, Executive Director, and Sharon Fallis, Associate Director, for their assistance in the preparation of this article.

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tools for Change

Tools For Change is an exciting new video-based curriculum that builds skills and knowledge in self-advocacy.

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Item #001

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CONGRATULATIONS

to Judith Snow, recipient of the 1997 DateAble Image Award for advocacy!

1997
dateable
Image Awards

On April 15, 1997, the DateAble Image Awards Dinner was held in Washington, D.C. The annual DateAble Image Awards are designed to raise consciousness concerning the abilities of people with disabilities. Along with Judith, this year's honorees included John Hockenberry (journalism) and The Hechinger Company (corporate).

BEST COPY AVAILABLE

1997 TASH AWARDS

IT'S TIME ONCE AGAIN TO SUBMIT TASH AWARD APPLICATIONS!

Every year at the annual conference, TASH confers a series of awards that recognize individuals, teams, organizations, or media mediums which exemplify the spirit and mission of TASH. Submit your application (found on the following two pages) today!

▶Who comes to mind when you think of someone who has made a positive difference in the lives of persons with significant disabilities over the past year?

▶Have you recently seen an outstanding media piece that embodies the values of TASH?

▶Do you know of a student enrolled in a doctoral program in education or a related field who demonstrates leadership, advocacy, and commitment to efforts of individuals with disabilities?

▶Is there a team of people working together to improve the quality of life for a person(s) with disabilities?

This is your chance to honor such accomplishments with official recognition. Please take the time to submit an application. Awards will be conferred as part of the TASH Annual Conference to be held in Boston, December 10-13, 1997. Award applications will be accepted through July 31, 1997. **Please be sure to indicate for which award you are applying on the application, and submit all required documents or information requested for that award.**

1997 POSITIVE APPROACHES AWARD

This award is presented to the person whose contributions have served to advance non-aversive intervention with persons who display challenging behaviors; have demonstrated outstanding efforts leading to the understanding of challenging behavior, and whose actions have advanced the use of non-aversive interventions and progress in the use of positive behavioral supports.

1997 ALICE H. HAYDEN AWARD

This $500.00 cash award will be presented to a doctoral student enrolled in a program in education or a related field, who demonstrates potential for leadership in teaching, scholarship, and service on behalf of people with significant disabilities. The individual needs to have demonstrated a continuing desire in working in partnership with people with disabilities in accordance with TASH values.

1997 MEDIA AWARDS

This award is presented to honor presentations in either print or film, which best promote the inclusion of people with severe disabilities in all aspects of community life, and which have reached a national audience. Criteria for selection include: high quality, accuracy of information, meaningfulness of subject matter, potential for consciousness-raising, and promotion of quality of life for persons with disabilities.

1997 COLLABORATION AWARD

TASH will recognize collaborative teams of persons with disabilities, family members, professionals, community members and/or peers, who are engaged in projects and advocacy efforts to ensure the implementation of TASH values in their local community, or in a way that has affected others at a local, state, regional, and/or national level. The work of the recipients of this award should serve as an inspiration for other community efforts, and demonstrated creativity in supporting an individual or individuals to realize the goals of self-empowerment and full community inclusion.

For more information, please contact Denise Marshall at 1-800-482-8274 x103.

1997 TASH AWARD APPLICATION

- Applications due July 31, 1997 -

How to Apply:

(1) Complete this application form - front and back- as fully as possible.

(2) Attach a brief narrative discussing why the nomination is being made. Please see the other side of this form for a list of supporting information and materials that must be submitted for the particular award you choose below.

3) Please indicate for which award you are applying. **Check only one award.**

- ☐ Alice H. Hayden Award
- ☐ Collaboration Award
- ☐ Media Award
- ☐ Positive Approaches Award

(4) To be considered, the original completed application and supporting materials must be received in the TASH central office no later than July 31, 1997. Send to:

Awards Committee
TASH
29 West Susquehanna Avenue
Suite 210
Baltimore, MD 21204

(5) Questions concerning this form should be directed to Denise Marshall, (410) 828-8274 x103.

Person or Team Being Nominated:

Name of the Individual:

Street Address:

City:

State/Province: Country

Zip/Postal Code:

Daytime Telephone: ( )

Evening Telephone: ( )

Is this individual(s) a member of TASH?
☐ Yes ☐ No

Name of team members (more room on reverse side)

Street Address:

City:

State/Province: Country

Zip/Postal Code:

Daytime Telephone: ( )

Evening Telephone: ( )

Is this individual(s) a member of TASH?
☐ Yes ☐ No

Person Making the Nomination:

Name:

Relationship to the team/person:

Street Address: **City:**

State/Province: **Country** **Zip/Postal Code:**

Daytime Telephone: ( ) **Evening Telephone:**

FAX:( ) **E-mail:**

Please provide as much information as possible about the persons who are part of this team. Please use additional paper if necessary.

Name of Team Member: ______________________

Organization if applicable): ______________________

Street Address: ______________________

City: ______________________

State/Province: ______________ Country: ______________

Zip/Postal Code: ______________________

Daytime Telephone: (___) ______________________

Evening Telephone: (___) ______________________

Is this individual(s) a member of TASH?
☐ **Yes** ☐ **No**

***

Name of Team Member: ______________________

Organization (if applicable): ______________________

Street Address: ______________________

City: ______________________

State/Province: ______________ Country: ______________

Zip/Postal Code: ______________________

Daytime Telephone: (___) ______________________

Evening Telephone: (___) ______________________

Is this individual(s) a member of TASH?
☐ **Yes** ☐ **No**

***

Name of Team Member: ______________________

Organization (if applicable): ______________________

Street Address: ______________________

City: ______________________

State/Province: ______________ Country: ______________

Zip/Postal Code: ______________________

Daytime Telephone: (___) ______________________

Evening Telephone: (___) ______________________

Is this individual(s) a member of TASH?
☐ **Yes** ☐ **No**

***

MEDIA CONTACTS

Please provide on a separate sheet of paper, the names and addresses of local radio, television, or newspaper outlets that would be interested in covering the presentation of the award.

AWARD APPLICATION REQUIREMENTS

Collaboration Award:

1. Attach a narrative which describes: a) the goal of the team; b) the interaction of the team members; c) the roles of the individual himself/herself, the family, peers of the individual, and/or people who provide paid support; d) the outcome of the team's efforts; and e) a brief narrative about the individual or individuals who benefited from the collaboration.
2. Attach at least three (3) letters which support the nomination. These letters should present specific anecdotal information or data which conveys an accurate picture of how this collaborative effort met the criteria for the award.

Positive Approaches Award:

1. Attach a description of the nominee's background in the area of severe disabilities. Please include a resume/curriculum vitae if appropriate.
2. Attach evidence of contributions related to positive behavioral support.
3. Attach three (3) separate one page letters in support of the nomination.

Alice H. Hayden Award:

1. Attach a curriculum vitae outlining your history of: a) higher education (including major, minor, degree, date of completion); b) employment (including dates, duties, name of supervisor); c) research and publications.
2. Also attach 500-1000 word essay which describes: a) your current work on behalf of individuals with severe disabilities; b) your educational and professional objectives.
3. Attach at least three (3) letters which support the nomination. These letters should be from professors who are familiar with your qualifications. The letters should present specific data or anecdotal information which convey an accurate picture of your current achievements and potential for significant contributions to the field.

Media Award:

1. Please provide a brief description of the project, including the medium used (radio, television, newspaper, magazine):
2. If the nomination is in the film category, please indicate the length of the video in minutes.
3. Attach two copies of the nominee's work, or of the specific project being nominated. If the nomination is in the print category, the submission must be neat and legible. If the nomination is in the film category, two video copies (VHS 1/2") must accompany the nomination. The submitted work must be sufficient to demonstrate that the work meets or exceeds the criteria for the award.

Permission to show video submittals:

If the nomination is in the film category, please complete and sign the following to hereby grant permission to TASH to show:

(Title) ______________________,

as produced by ______________________,

for, but not restricted to, promotion of the TASH Media Awards and the 1997 Annual Conference. Similarly, as it applies to the promotion of the TASH Awards and the 1997 TASH Conference, the producers waive any monetary compensation .

Signature: ______________________

Observing Alertness and Responsiveness Among Infants with Multiple and Severe Disabilities:

Some Interesting Observations for Parents of Young Children & Early Intervention Specialists

Doug Guess, Sally Roberts, and Jennifer Holvoet
University of Kansas

Jane Rues
Rockhurst College

Sophie is a beautiful little girl with natural curls and big brown eyes. Now almost five, we first saw her at a year and a half when she became a participant in Project Jay-Rock, a longitudinal research study that is a cooperative effort between the University of Kansas, Department of Special Education, and the Rockhurst College, Department of Occupational Therapy Education. Sophie was born with severe congenital encephalopathy, that resulted in a seizure disorder, severe spastic cerebral palsy, and significant developmental delays.

Our observations of Sophie began at a day care for children with disabilities, where she received occupational therapy three times a week for thirty minutes. That was the extent of her early intervention, and most of her care was medical in nature. Her mother has since quit her full-time job to spend more time with Sophie, and to allow time to advocate for better current and future placement and programming options. A little sister has since been added to the family.

We now observe Sophie in her new home, a one-level instead of the two story house we first visited. She has had repeated hospitalizations in the past three years, and acquired a gastrostomy tube. Her health appears to be stabilizing and the seizures are under control. We have watched her move from a baby with hypotonic (floppy) muscle tone, to a preschooler with hypertonic (spastic) tone. Her behavior state has also stabilized. Where she was sleepy and drowsy during most of the early observations, she now appears to be alert and orienting. While this behavior state is desirable, she still displays limited physical interaction with her environment.

In prior research studies, we observed and analyzed the amount of time that older children and youth with multiple and severe disabilities were alert and responsive to their classroom environments during daytime hours (Guess, Siegel-Causey, Roberts, Guy, Ault, & Rues, 1993; Guess, D., Siegel-Causey, E., Roberts, S., Guy, B., Ault, M. M., & Rues, J., 1993; Guess, Roberts, Siegel-Causey, & Rues, 1995). Our studies consistently showed that these students averaged slightly less than 60% of time in alert and responding states. Alertness was recorded when the students actively attended to their immediate surroundings. Responsiveness was recorded when they physically interacted with persons or objects in the classroom. In the remaining 40% of time, these students were observed in states less optimal for learning, ranging from sleep and drowsiness to excessive agitation. These findings were consistent with earlier observations of teachers (Thompson & Guess,1989), who expressed the need for better instructional procedures and strategies to address problems of alertness and responsiveness among their students with severe and multiple disabilities.

Additional results from these earlier investigations indicated that participants were somewhat consistent in their displays of these behaviors, allowing us to identify particular "profiles" or patterns. Some students spent most of their time alerting to, and interacting with, their surroundings. Other students spent considerable time attending to their surroundings, but spent less time physically engaging objects and materials. These students, like Sophie, often had severe motor impairments. Another group was comprised of participants who were observed for long periods in more active states that included crying/ agitation, stereotypic movements[1] and, in several cases, self-injurious behavior. Participants in a fourth and larger profile group were observed sleeping and drowsing for excessively long periods of time during daytime hours.

These findings are of considerable concern because excessive amounts of time spent in behavior states other than alerting and responding, reduce learning opportunities for these students. More importantly, excessive time in some of these observed states (e.g., crying/ agitation, sleeping, drowsing) negatively impacts their overall quality-of-life. State patterns of excessive sleep and drowsiness, excessive stereotypy and crying/ agitation, or low occurrences of responding are, in fact, a major contributing factor to the presence of related behaviors associated with the perception of severe and profound disability. We further observed that, once established, these nonoptimal behavior state patterns are difficult to change, with only modest success from extensive intervention efforts (Ault, Guy, Guess, Bashinski, & Roberts, 1995). It became apparent to us

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RESPONSIVENESS OBSERVATIONS AMOUNG INFANTS

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that preventing the initial emergence and solidification of these nonoptimal state patterns is likely necessary for addressing the problem. Therefore, it was important for us to know how and when behavior state patterns emerged among infants and young children with identified significant disabilities. Further, what types of variables, if any, are associated with the emergence of these patterns?

To address these questions, we received support for a longitudinal study[2] (started in 1993) to identify, across time, emerging behavior state patterns among infants and young children who, at birth (or shortly after), were identified as having a significant disability. This investigation includes 34 infants and young children with multiple and severe disabilities and, earlier in the study, five normally developing infants who were observed during their first year of life. (Since the beginning of the study, nine of the participants have died from conditions associated with their severe disabilities.) A 13-category code is used to collect bi-monthly behavior state data in one-hour observation sessions; across years, and in natural home, day-care, and intervention settings. Another code is used simultaneously to collect environmental data on events and conditions that include body position, type and availability of materials, type and duration of interactions with the participants, etc. Developmental data (i.e., motor, sensory, communication, and emotional milestones) are recorded at each observation session, and a large multiple-category form is used to compile pre- and post-birth medical and health-related information on each participant.

Although data collection is not completed, we have noted several interesting trends. We find, for example, that 14 participants are already identified to be in the same state profile for at least four out of their last five observation sessions. The average age on their last observation session was 2 years, 6 months (range from 1 to 4 years). Only one of the 14 participants, however, was consistently observed in the state profile pattern with high percents of alerting and responding behavior—a profile pattern reached by all five of the normally developing infants well before they turned one. The remaining 13 participants were observed in profile patterns with high occurrences of alerting, but not interacting behaviors; or, they spent considerable time in the sleeping, drowsiness, crying/agitation, and stereotypy states. We have also observed, even at this early age, profile differences in motor and communication characteristics, similar to the profile differences found in our investigations with older children and youth identified as having multiple and severe disabilities.

Our final data analysis will include influences on emerging state patterns from the environment, medical and health conditions, and developmental histories. As part of this analysis, we also will try to identify very early conditions and events that appear to contribute to the later emergence of state profile consistency. This will allow us to better reach our major goal, which is the identification and/or development of intervention strategies and approaches that will, early on, move infants with multiple and severe disabilities into more optimal levels of alertness and responsiveness. If successful, these interventions will direct attention to increasing levels of alertness and responsiveness as outcome measures for improving significantly these children's overall quality of life. And this, we believe, is a most worthwhile pursuit for these children!

Interested in learning how to collect behavior state and learning environments data? If so, contact Susan Bashinski at The University of Kansas, Department of Special Education *(913) 864-4954*, for information regarding the Analyzing Behavior State in Learning Environments (ABLE) Inservice Training Program. The ABLE program is an entirely self-contained, CD-ROM based, multimedia training package for the Mac platform that provides: information regarding state, nutrition, medication, and environmental characteristics, coding practice opportunities, and simulated case studies for application of the ABLE Assessment and Intervention Model.

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Guess, D., Roberts, S., Siegel-Causey, E. & Rues, J. (1995). Replication and extended analysis of behavior state, environmental events, and related variables in profound disabilities. *American Journal on Mental Retardation* (accepted for publication).

Guess, D., Roberts, S., Siegel-Causey, E., Ault, M. M., Guy, B., Thompson, B., & Rues, J. 1993). An analysis of behavior state conditions and associated environmental variables among students with profound handicaps. *American Journal on Mental Retardation*, 97, 634-653.

Guess, D., Siegel-Causey, E., Roberts, S., Guy, B., Ault, M. M., & Rues, J. (1993). Analysis of state organizational patterns among students with profound disabilities. *The Journal of Association for Persons with Severe Handicaps, 18*(2), 93-108.

Guy, B., Guess, D., & Ault, M. M. (1993). Classroom procedures for the measurement of behavior state among students with profound disabilities. *The Journal of the Association or Persons with Severe Handicaps, 18*, 52-60.

Thompson, B. & Guess, D. (1989). Students who experience the most profound disabilities: Teacher perspectives. In F. Brown & D. Lehr (Eds.), Persons with profound disabilities: Issues and practices (pp. 3-42). Baltimore: Paul H. Brookes Publishing Co., Inc.

Footnotes

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[1] We recognize, also, the importance that stereotypy has in normal development, and as a later regulatory function for persons in under- and overstimulating environments.

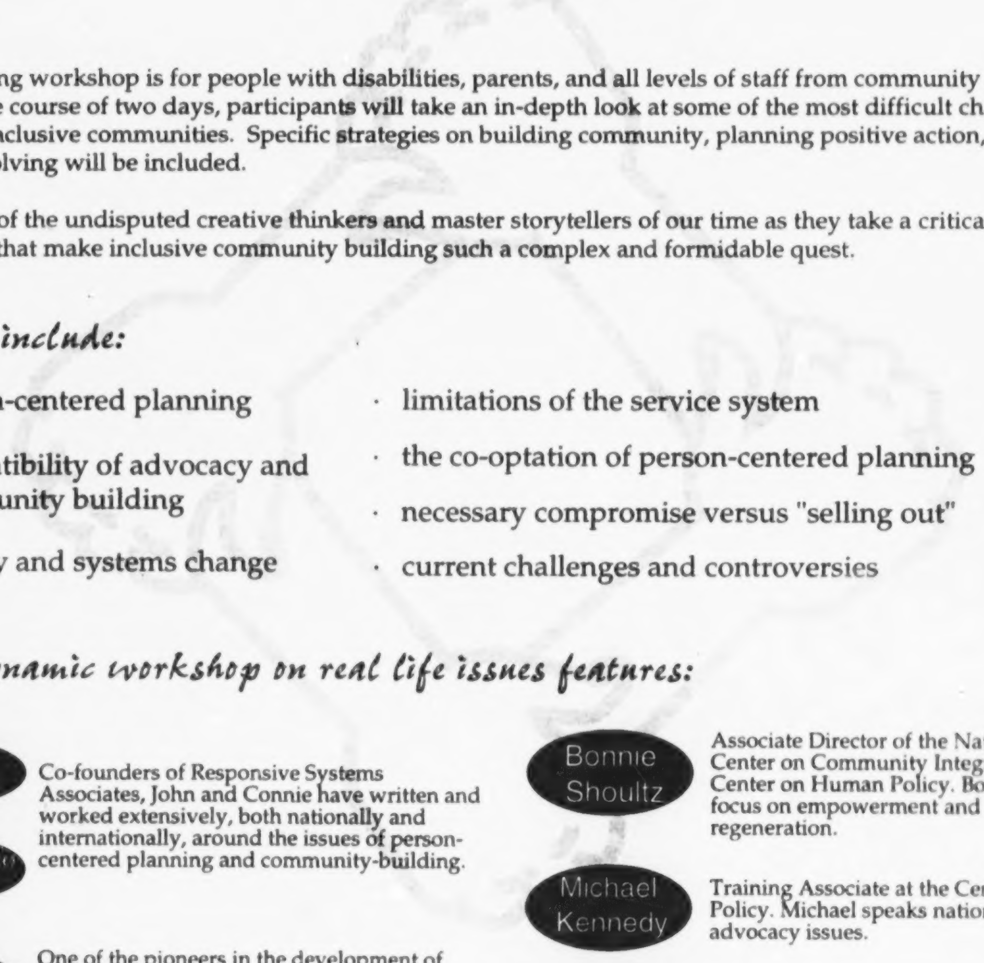
[2] This research is supported by a grant from the U. S. Department of Special Education, Research in Education of Individuals with Disabilities Program, "Longitudinal Assessment of Emerging Behavior State Patterns Among Infants and Children with Severe and Profound Disabilities" (H023c30029).

The Complexities of Community-Building

A workshop co-sponsored by
TASH and the Center on Human Policy

July 15-16, 1997 · Syracuse, NY

9:00 AM - 4:00 PM



This exciting workshop is for people with disabilities, parents, and all levels of staff from community agencies. During the course of two days, participants will take an in-depth look at some of the most difficult challenges in building inclusive communities. Specific strategies on building community, planning positive action, and problem-solving will be included.

Join some of the undisputed creative thinkers and master storytellers of our time as they take a critical look into the issues that make inclusive community building such a complex and formidable quest.

Topics include:

- person-centered planning
- compatibility of advocacy and community building
- agency and systems change
- limitations of the service system
- the co-optation of person-centered planning
- necessary compromise versus "selling out"
- current challenges and controversies

This dynamic workshop on real life issues features:

John O'Brien and **Connie Lyle O'Brien** Co-founders of Responsive Systems Associates, John and Connie have written and worked extensively, both nationally and internationally, around the issues of person-centered planning and community-building.

Beth Mount One of the pioneers in the development of person-centered planning. Beth has consulted with many agencies on issues related to person-centered planning and agency change.

Steve Taylor Director of the Center on Human Policy. Steve is especially interested in examining the relationship between advocacy and community-building.

Bonnie Shoultz Associate Director of the National Resource Center on Community Integration at the Center on Human Policy. Bonnie's interests focus on empowerment and community regeneration.

Michael Kennedy Training Associate at the Center on Human Policy. Michael speaks nationally on self-advocacy issues.

Pam Walker Research Associate at the Center on Human Policy. Pam is interested in community supports and community-building.

And... other Center on Human Policy Staff

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Hotel Accommodations

GENESEE INN, 1060 E. Genesee St., Syracuse, NY 13210, at a cost of $49/night for a single, $59/night for a double. A block of rooms will be held until July 1. Call the hotel at 315-476-4212 to make reservations. Please indicate that you will be with the Center on Human Policy/TASH workshop.

Fees

The fee for this two-day workshop is $97. Groups of five or more registering together, $89/person. When using a group discount, all registration forms must be mailed together, with payment, prior to July 1st. A limited number of stipends are available for self-advocates and parents. Scholarships will be assigned on a first-come-first-served basis.

The ***Center on Human Policy*** is designed to promote the full inclusion of people with developmental disabilities in community life. Funded by the National Institute on Disability and Rehabilitation Research (U.S. Department of Education), the National Resource Center continues the Center on Human Policy's work in the area of training, technical assistance, consultation and information dissemination. *For more information on the Center On Human Policy call 315-443-3851 or visit our website at http://soeweb.syr.edu/thechp/*

Registration Form

Please Print - Use this form for one individual's registration only. Make copies to register additional participants.

First Name Last Name

Agency (if applicable) Address

City State/Province Zip/Postal Code

Daytime Phone Fax e-mail

☐ Check Enclosed ☐ Visa
☐ Mastercard ☐ Discover

Card #

Expiration Date

Name on Card

Signature

· Regular Registration	$97	______
· Group Discount Rate	$89	______
· Add late fee for each registration postmarked after June 25, 1997	$20	______
· Optional Lunch - includes meal for both days	$15	______
TOTAL ENCLOSED (Payment must be enclosed with registration)		______

☐ Please specify needs for interpreter services, accessibility supports or dietary requirements ______

Please Note: Checks must be drawn on a US Bank. $25 cancellation fee before June 30, 1997. Thereafter, no refunds can be granted.

Mail form and payment to:

TASH
CHP/TASH Workshop
29 West Susquehanna Avenue, Suite 210
Baltimore, MD 21204

For More Information:

Please call Denise Marshall at 410-828-8274 ext.103 or e-mail her at dmarsh@tash.org

1997 TASH ANNUAL CONFERENCE

Join us in the city where the right to life and liberty was secured and help to ensure that every individual has the right and equal access to full inclusion in society.

The 1997 TASH Conference is in Boston, a city with an impressive history inspiring action. A perfect match for an organization known for the same! "Inclusion" is not necessarily a revolutionary idea. However, the actual realization of true inclusion still has many miles to go, and there are still many battles to win. This is the opportunity to learn and share from the people whose combination of personal experience and professional expertise have led the disability movement. Over 2,400 advocates, educators, disability leaders, university personnel, community members, family members, and others who believe in the values you do attend the TASH Conference.

Mark your calendars now and watch for the official brochure in the next few weeks. For more information, call 1-800-482-8274 or e-mail us at conference @ tash.org

Pre-conference Full Day TASH TECH Workshops Dec 10, 1997

T1 **Issues Connected with Setting Standards for Paraeducator Roles, Skills, and Preparation** *Patricia Mueller, Anna Lou Pickett*

T2 **Inclusive Classrooms as Total Learning Communities** *Mara Sapon-Shevin, Mary Fisher, Lucille Zeph*

T3 **Seeing Competence: Challenge Our Deficit Approach to Understanding and Supporting Individuals with Austin/ Mental Retardation and Other Severe Communication, Movement and Behavior Challenges** *Anne Donnellan, Phillip David Zelazo, Margaret Bauman, Michael J. Solomon Weiss, Martha Leary, Karen Strandt-Conroy, Sally Young, Madeline Hafner, Jean Hauser, Victoria Moerchen*

T4 **Public Schools and the American with Disabilities Act (ADA)** *Kathy Gips, Melissa Marshall*

T5 **Curriculum Modification and Communication Supports TOGETHER in the Inclusive Classroom** *Cheryl Jorgensen, Rae Sonnenmeier*

T6 **Specific Strategies to Support Friendships and Community Connections for People with and Without Disabilities** *Angela Novak Amado*

T7 **Including Students with Disabilities as Fully Participating Members of the High School Community** *Carol Tashie, Mary Schuh, Susan Shapiro-Bernard*

T8 **Accessing the Opportunities of Whole Class Instruction in Inclusive Classrooms** *Christine Salisbury , Ginger Joyce, Toni Strieker, Deborah Tweitt-Hull*

T9 **Preparing Teachers for Inclusive Schools: Strategies for Change within Higher Education** *Gail McGregor , Dianne Ferguson, Alison Ford, Beverly Mattson*

T11 **Homeownership: A National Initiative** *Jay Klein, Marcie Goldstein, Judith Snow, Joe Wykowski*

T10 **Assistive Technology: From Policy to Reality** *Katherine Inge, Karen Flippo, Jay Klein, Marcie Goldstein, Judith Snow, Joe Wykowski*

T12 **From Paternalism to Receprocity: Putting "A Credo of Support" into Daily Practice** *Mayer Shevin, Nancy Kalina*

T13 **Making Meetings Matter** *Marsha Forest, Jack Pearpoint*

T14 **Changing a Human Service Agency** *Jeff Strully, Tara Asai, Patricia Fratangelo*

T15 **The Process of Positive Behavioral Support with Families in Natural Contexts** *Bobbie Vaughn , Kathy Ben, Glen Dunlap, Joseph Lucyshyn*

T16 **Family-centered Approaches in Early Childhood** *Susan Yuan*

T17 **Implementing I.D.E.A. following Reauthorization: Implications for Students, Families, and Schools** *Kathy Boundy, Eileen Ordover, Frank Laski, Tom Gilhool, Judy Gran*

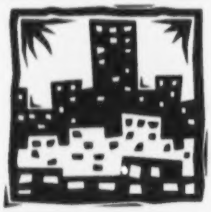
TC **TASH Chapter Development and Leadership Day** *A free workshop for TASH Chapter representatives and people interested in forming a TASH Chapter*

TASH Chapter Development and Leadership Day
This free session is offered to TASH Chapter Officers, chapter members, and people interested in forming a TASH Chapter. This session will be an interactive day focusing on chapter organization and administration, fundraising, membership drives, grassroots organizing, legislative action, advocacy strategies and much more. You must register in advance. Registrants for this workshop will receive lunch at the pre-conference workshop and 25% off the cost of registration for the full conference. Sign Up Now!

US Airways has been designated as the official carrier for attendees of the TASH Conference. US Airways agrees to offer an exclusive low fare. This special fare will offer a 5% discount off First Class and any published US Airways promotional round trip fare. A 10% discount off unrestricted coach fares will apply with, 7 days advance reservations and ticketing required. These discounts are valid provided all rules and restrictions are met and are applicable for travel from all points on the US Airways route system.

The above discounts are not combinable with any other discounts or promotions, and are valid between December 5-17, 1997. To obtain the discounts, you or your travel agent must call US Airways Meeting and Convention Reservation Office at 800-334-8644; 8:00 AM - 9:00 PM Eastern Time. Refer to Gold File No. 77680250

Last year over 50 people disabilities and or family members of people with disabilities were able to attend the conference because you stayed at the TASH headquarters hotel and/or used the official airline. Thank you! Let's continue that effort and make it possible for even more people to attend this year's conference in Boston. Make your reservations early - the holiday season is a busy time for an exciting place like Boston - don't delay, do it today!



SHERATON BOSTON HOTEL & TOWERS
39 Dalton Street
Boston, Massachusetts 02199
(617) 236-2000

1997 Hotel Rates
$129.00 Single Occupancy
$137.00 Double Occupancy

TASH Conference Registration Form

"We the People, *ALL* the People"

Sheraton Boston, December 10 - 13, 1997

Mail form to: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204-5201
Fax form to: TASH, (410) 828-6706.TDD (410) 828-1306 • Questions? Call 1-800-482-TASH
The registration application can also be found at http://www.tash.org

Registration Discounts

10% Earlybird Discount for Registrations postmarked by September 15, 1997.
10% Discount for groups of 5 or more registering together (must be mailed and received in the same envelope)
50% discount off the rate that applies (for each person) for a regular education teacher registering with a special education teacher, a paraprofessional, or related services personnel, or for any support staff person registering with a self advocate (must be mailed and received in the same envelope).

*Only one discount in addition to the earlybird discount is allowed

You may use this form to register for the conference only; register for the conference and become a TASH Member at the same time; or to become a member only.

Please Print

Last Name ______________________ First Name ______________________

Preferred Badge Name ______________________

Agency/School/University ______________________

Mailing Address ______________________

City/State/Province ____________ Zip/Postal Code ________ Country ____________

Billing Address ______________________

City/State/Province ____________ Zip/Postal Code ________ Country ____________

Daytime Telephone ____________ FAX ____________

E-mail ______________________

Please enter the code off the brochure mailing label (if applicable) ________

Please Circle the Appropriate Number(s)

1 University/College Educator
2 Special Education Teacher
3 Professional Development
4 College Student
5 OT/PT
6 Legal Advocate
7 Regular Education Teacher
8 Administrator
9 Social Worker
10 Speech/Language Pathologist
11 Family Member/Parent
12 Self-Advocate
13 Support Services Provider
14 Government Personnel
15 Supported Employment
16 Psychologist
17 Early Childhood
18 Other

Please fill out this section only if you are registering for the conference:

TASH Membership: ☐ Individual ☐ Agency Membership #____________

(please note: up to three persons can register at the membership rate using an agency membership)

Student ID# (if applicable) ______________________

☐ I am becoming a member now
☐ Please check here if you are a TASH Lifetime Member with Conference Privileges
☐ Please check here if the address above is a new address

Optional Service Information Requested (please request be November 1)

☐ Accessibility Details
☐ Sign Language Interpretor
☐ CEU Credits
☐ Child Care/Youth Activities (Note: you must fill out an application in advance to register. Space is limited)
☐ Roommate Referral Program
☐ List any accommodation needs ______________________

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To Become a TASH Member NOW. . .

You may also use this form to become a member at the same time you register for the TASH conference! This allows you to register for the conference at the reduced TASH member rate (see other side for member registration rates) or, *use this form to join as a member without registering for the conference.*

Membership rates are listed below. Determine the appropriate membership category, be sure to fill in the applicable rate on the reverse side of this form when entering payment information, and include payment at the time you submit your conference registration payment.

General International Membership (individuals)	$85.00
Agency/Business/University International Membership	$190.00
Self-Advocate, Parent, Full -Time Student, Direct Support Worker, Paraprofessional, Personal Attendant, International Membership	$45.00
Family International Membership (2 people)	$130.00
Lifetime International Membership	$1,000.00

(Add $15.00 to memberships outside of the U.S. and Canada to cover additional postage costs)

Fill in appropriate membership rate on Line 4 on reverse side of this form.

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CONFERENCE REGISTRATION FORM

1997 TASH CONFERENCE - "WE THE PEOPLE, ALL THE PEOPLE" - DECEMBER 10-13

Registration Rates 1997 Conference	Current or Joining International Member	Non-Member	Please Enter Applicable Cost
General Members	$169	$289	
Student/Paraprofessional/Parent Members (Professional)	$135	$229	
Family (2 People)	$204	$420	
Self Advocate/Parent (non-professional)	$ 29	$ 39	
One Day ☐ Thurs ☐ Fri ☐ Sat	$ 99	$129	

1. Cost for Conference Registration from above .... 1. ________

- Less 10% Discount for Earlybird Registrations (must be postmarked by Sept. 15th) .... ________
- Less 10% for Group Discount or 50% for other discounts .... ________
- Please enter if applicable, see other side for details **(only one discount in addition to earlybird discount is allowed)**

Add discounts .... ________

2. Total Conference Registration Rate (Subtract discounts from line 1) .... 2. ________

Rates to add a Pre-conference Full Day TASH Tech Workshop (see descriptions, pg. 28)

TASH Members	$65.00
Non-Members	$75.00
Self advocate/Parent	$40.00

NOTE: There is no charge for the Chapter Leadership Tash Tech.

1st Choice Tech # ______
2nd Choice Tech # ______

3. Add Cost of TASH Tech if applicable .... 3. ________

4. TASH Membership Dues Enclosed (If joining or renewing with this application, add applicable rate from other side) ..... 4. ________

5. To Join Your State Chapter Add $15.00 (only applicable if joining now) .... 5. ________

6. Yes I will donate $5.00 to support a self-advocate to attend the conference .... 6. ________

Grand Total Enclosed (add applicable costs for lines 2-6) ________

Payment Terms

Registration will not be accepted without payment by check, official purchase order, or credit card authorization. Please note that payment must be in U.S. Funds only. A $25.00 processing fee will be deducted from cancellations received before November 15, 1997, and added to purchase orders not paid within 30 days after the conference. No refunds will be given for cancellations after November 15, 1997. After that date, registrations will be on-site only and a $35.00 processing fee will be added to all registrations. A $15.00 fee for returned checks or unauthorized charges will be assessed.

☐ Check enclosed ☐ Purchase Order/State Voucher No. ____________________

☐ Visa ☐ Mastercard ☐ Discover Card Number ____________________ Exp Date ____________

Signature ____

LINN-BENTON-LINCOLN EDUCATION SERVICE DISTRICT

Seeks Itinerant Consultant for Autism. 190-day contract structured to the school calendar, with non-work days scheduled during the winter break, spring break, and summer weeks; plus holidays.

Competitive salary based upon education and experience in accordance with the terms of the Collective Bargaining Agreement, with attractive fringe benefit package.

Must possess a Master's Degree in Special Education and be eligible for Oregon Teacher Standards & Practices Commission license, with Handicapped Learner endorsement.

Education Service District is located in the beautiful Willamette Valley; affordable living. Metropolitan areas, universities, beach, and mountains all within one hour's drive.

For application materials, write to: Personnel Office, Linn-Benton-Lincoln ESD, 905 4th Avenue SE, Albany, OR 97321-3199 or *phone: (541) 967-8822*

The University of Washington Graduate Program trains teachers to serve the needs of pupils with significant disabilities. Emphasis on data-based, systematic instruction referenced to the requirements of natural school and community settings. M.Ed. degree plus initial teacher certification possible.

Dr. Felix Billingsley, Area of Special Education,
102 Miller Hall, Box 353600, University of Washington,
Seattle, WA 98195, Phone (206) 432-1827
e-mail felixb@u.washington.edu

SPEECH-LANGUAGE PATHOLOGIST

Participate in the development of assistive or alternative communication systems for students preschool through 21 years of age living in a multi-county region. ASHA certification or a suitable alternative required.

190-day contract structured to school year; competitive salary with fringe benefits. Located in the beautiful Willamette Valley; affordable living. Metropolitan areas, universities, beach, and mountains all within one hour's drive.

Contact Personnel, Linn-Benton-Lincoln Education Service District (EOE), 905 4th Avenue SE, Albany, OR 97321-3199 or ***phone (541) 967-8822***.

Special Education Service Agency (SESA)

Based in Anchorage, is looking for teachers with advanced training and experience to work independently and collaboratively with other professionals in cross cultural settings. Requires travel to rural and remote villages in Alaska. Prefer experience with teacher training and support and interagency networking.

Multiple Disabilities

Master's level special education teachers with specialized training and a minimum of three years recent experience in at least two of the following: multiple disabilities, autism, orthopedic and other health impairments, mental retardation, traumatic brain injury and preschool developmental disabilities. Working knowledge of inclusion, positive behavior supports, alternative communication, community-based instruction and/or vocational development is a must. Familiarity with current technologies in communications, productivity and education required. Salary range: $39,402 - $51,133 DOE

Contact:

Ron Jones, Program Administrator
2217 E. Tudor Road, Suite 1, Anchorage, AK 99507
(907) 562-7372 (voice) or (907) 563-8284 (TTY)

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on language "that emphasizes the humanity of people with handicaps." Terms such as "the autistic," "the retarded," and "the severely handicapped" refer to characteristics, not individuals. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Executive Board

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Liz Healey, *Chair of the Executive Committee*
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MEMBERSHIP INFORMATION

Funds must be submitted in U.S. Dollars.

Name: ______________________________

Address: ______________________________

City/State/Zip: ______________________________

Telephone: (   ) ________________ Fax: (   ) ________________

Please Check Appropriate Categories (not more than three):

( ) Administrator/Adult Services
( ) Administrator/Education
( ) Adult Services Provider/Staff
( ) Behavioral Specialist
( ) Case Manager
( ) Early Childhood Services
( ) Educator (College/University)
( ) Government Personnel
( ) Interested Individual/Advocate/Friend
( ) Legal Services Provider
( ) Occupational/Physical Therapist
( ) Parent/Family Member
( ) Personal Assistant
( ) Professional/Public Policy Advocate
( ) Psychologist
( ) Regular Education Teacher/Administrator
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Special Education Teacher/Support Specialist
( ) Staff Development/Trainer
( ) Student
( ) Supported Employment/Day Personnel
( ) Other

General Membership (individual)	$85.
Agency/business/university/college/library/school (allows three conference attendees)	$190.
Self Advocate, Parent, Full Time Student, Direct Careworker/Paraprofessional/Personal Attendant (for whom payment of full fee would present a hardship)	$45.
Family (group rate)	$130.
Lifetime Member:	$1000.

All dues are $15 higher for members outside the U.S. & Canada.

If you would like to charge your membership, please fill in the necessary information:

( ) MASTERCARD ( ) VISA ( ) DISCOVER

Card Number ______________________________

Expiration Date ______________________________

Signature ______________________________

( ) I would like to arrange to spread my payments out. Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

How did you learn of TASH: ______________________________

What, in particular, inspired you to join: ______________________________

What other disability organizations do you belong to: ______________________________

Referred by: ______________________________

If you are applying for a student membership, please provide the following information:

Department ______________________________

College/University ______________________________

Student I.D. Number ______________________________

Anticipated year of completion ______________________________

( ) Please check here if you would like us to send information about your local TASH Chapter.

Please make check payable to: **TASH**
Address: **29 W. Susquehanna Avenue**
Suite 210
Baltimore MD 21204
Telephone: **410/828-8274 Fax: 410/828-6706**

MOVING?
***Please notify* TASH**
of your new address.

TASH
29 West Susquehanna Avenue, Suite 210
Baltimore, MD 21204
Phone: 410/828-8274, FAX: 410/828-6706, TDD: 410/828-1306

Address Correction Requested

MAY 1997

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Newsletter

Important!
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INSIDE!
TASH Board
Election
Ballot

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BY FRANK LASKI

David Hingsburger's personal account of the Special Olympics International skating competition (TASH *Newsletter*, May 1997) and the responses by Mary Ulrich, Jo Ann Simons, and others (pages 5-6, 30 of this *Newsletter*), are thought-provoking and should rekindle serious dialogue not only about Olympic-level competition, but the full range of sports, athletics, and recreation and leisure pursuits available in our communities.

■

Our experience in schools, community parks and recreation departments, Boy Scouts, YWCA's Jewish Community Centers, 4-H groups, and other recreational settings drives us in the same direction - inclusion. Our experience also puts us on a collision course with any enterprise that symbolizes and promotes a handicapped-only culture and seems rooted in the "special" era. It does not put us at unalterable odds with the athletes and their families who choose to participate under the logo of these programs.

■

Special Olympics was founded in — and is fundamentally bounded by — its mission to provide sports training and athletic competition for individuals with mental retardation. In the beginning (the first Special Olympic Games were held in Chicago in 1968), the Games provided a highly visible demonstration of the athletic capabilities and sports skills of people with mental retardation. In this way, Special Olympics was akin to Marc Gold's early work and the Oregon Specialized Training Programs that demonstrated productivity and employment potential in segregated settings. Upon recognizing that these capabilities were greater than most professionals and experts believed, TASH, through its research, training, and advocacy worked to enable individuals to use their skills in integrated settings.

Along the way, we debated tactics and trade-offs and learned from our accumulated research and practice that:

- the benefits that people gained in segregated settings (e.g. sports proficiencies and earned income) could be equaled and exceeded in integrated surroundings; and

- integration with people who do not have disabilities was a necessary condition to achieving many other valued outcomes such as upgrading skills, increasing choice of community activities, and encouraging self-confidence and active participation.

The strength and validity of these teachings over the past two decades have leveled the playing field for persons with disabilities in schools, work, and community living. The progress toward totally inclusive participation is solid and irreversible.

Our experience in schools, community parks and recreation departments, Boy Scouts, YWCA's Jewish Community Centers, 4-H groups, and other recreational settings drives us in the same direction: inclusion. Our experience also puts us on a collision course with any enterprise that symbolizes and promotes a handicapped-only culture and seems rooted in the "special" era. It does not put us at unalterable odds with the athletes and their families who choose to participate under the logo of these programs.

In 1996, some 450,000 persons with mental retardation in the U.S. participated in Special Olympics-sponsored events involving over 500,000 volunteers. There is no denying that all these individuals, like JoAnn Simons' son, Jonathan, benefit substantially from improved physical fitness, self-confidence, and increased family and community support. That in 1997 these benefits are primarily – and for some, only – available through a handicapped-only charitable enterprise is not merely problematic, but ultimately untenable.

The issues surfaced by David, Mary, Jo Ann, and others transcend Special Olympics, but cannot be addressed in any practical sense without engaging the many supporters, volunteers and participants in the program. TASH, it appears, needs to renew the dialogue that former President Martha Snell, Mary Ulrich and Stuart Schlein began some years ago. The gist of the exchange is captured in the transcript of a past TASH Board meeting (see sidebar, page 3).

Unified Sports, which combines athletes with and without retardation on teams, is not the standard today nor is it likely to be in the short-term future under the Special Olympics logo. Nevertheless, we should acknowledge and encourage those programs that are unified, or those that pair students with athletes for peer coaching or purposefully involve youth with disabilities in school and community teams.

For all its symbolic importance and real influence, we should not allow the omnipresence of Special Olympics to cloud our vision or limit our purpose. Those purposes are better informed by a civil rights anniversary we celebrated this June.

Twenty-five years ago we banned sex discrimination in publicly-funded education programs (Title IX, 1972). In 1972, 1 out of every 27 girls of high school age participated in sports. Today, 1 out of every 3 girls play high school sports. Other measures (e.g. college sports scholarships) show Title IX to be a highly effective tool for not only leveling the playing field, but redefining it. A year after Title IX, Congress banned disability discrimination (Sec. 504) across all federally-funded programs, and in 1990 strengthened and expanded the ban in the ADA.

Surely, just as women, we can point to some measure of increased participation and acceptance in a variety of sports and recreational pursuits. We would be hard-pressed to demonstrate any fundamental alteration of '60s models that yet predominate and, by and large, separate.

Given the impact of Title IX, the potential of the ADA, and the state-of-the-art that unified games and integrated recreation represent, there is common ground for all – beneficiaries of Special Olympics or not – to join together to achieve a real measure of integrated recreation.

Excerpts from a transcript of a past TASH Board meeting contained the following discussion about Special Olympics

TASH Board Member: "Is there some way the Kennedy Foundation could give the Kennedy name back to integrated P.E. programs in public schools for all children for life?"

Kennedy Foundation representative: "The Kennedy Foundation is clearly in that corner."

TASH Board Member: "You are right. When Special Olympics came in, it met a need that was not being met any other way, in much the same way that special schools were a progressive development when large numbers of children were not in school at all. The wave of the future is integration. We would agree with you on that.

Nevertheless, we have to face the difficult problem of what to do about Special Olympics in much the same way we have to face the problem of what to do about special schools, or special classes. I think we do have to have a new language to go along with the new step. Maybe it is unified sports, maybe it is cooperative sports movements. But I think we have to come up with a language that describes a cooperative sports effort, that calls upon all kinds of people to participate, and that gives people a vision of what that would look like.

I think it is a mistake for us to continue to foster Special Olympics simply because it has its place. I think we need to move away from that very, very quickly. To do this effectively, we need a new vision for the future. We are going to have an alternative movement that can carry us forward and achieve that image."

Kennedy Foundation representative: "We are trying to move in the direction of the Unified Sports Program, and I think that the Unified Sports Program will become the standard."

TASH Members Speak Out On Special Olympics

BY NANCY WEISS

TASH received a number of letters in response to the article by Dave Hingsburger on Special Olympics in last month's issue of the *Newsletter*. It is clear that the article raised strong emotions on both sides of the issue.

Hingsburger's article describes one advocate's change of opinion when he experienced the Special Olympic World Games first-hand. Hingsburger chronicles his conversion from one who shared a negative perception of segregated sports to a supporter of the pride-in-self and pride-in-purpose that the events generated for participants.

TASH does not support segregated sports. However, it is important to open discussion to a range of points of view. Although members may generally share the same set of ideals, each of us is somewhere along the path toward accomplishing those ideals. TASH strives to advocate for a better future without alienating those who struggle with the realities and resource constraints of everyday life.

The discussion in response to this article has brought an important issue back into focus. In the late 1980's, TASH members were working actively with Special Olympics, Inc. to move toward inclusive models (see Frank Laski's article on pages 2-3). As described by Cynthia Burkhour (Letters to the Editor, pages 5-6, 30), TASH members continue to work to make a broader range of inclusive options available to all people with disabilities. It may be time to renew our efforts to work with representatives of Special Olympics, Inc. in an attempt to shape the future of their programs.

The Recreation and Leisure Interest and Action Group has organized a strand on inclusive recreational opportunities at the TASH annual conference in Boston in December. Plans for the strand include an Integrated Sports Roundtable. One of the goals for the Roundtable is the consideration of a plan for taking a more active role with Special Olympics, Inc. If you are interested in participating in such a forum, please fax or call Cynthia Burkhour at 616-669-9109 or send Cynthia an e-mail at AccessRecreationGroup@juno.com

Letters to the Editor begin on Page 5

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TASH (The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services.

EDITOR'S NOTES

TASH endeavors to provide the monthly *Newsletter* as a forum for the exchange of information, resources, meeting and networking opportunities, and personal perspectives on a number of issues important to our members. This month's issue accomplishes that aim on a number of levels, beginning with the many letters TASH has received in response to David Hingsburger's article (May 1997 *Newsletter*) on his recent experience with Special Olympics.

This issue also contains several feature articles on supported employment and conversion studies. Pat Rogan, Susan Rinne, and Mary Held discuss preliminary results of a study on strategies for changing from facility-based to community-based supports in employment settings (page 9). Beginning on page 13, Leslie Wilson describes the flaws of segregated day services and suggests flexible alternatives to such programs. Michael West, Paul Wehman, Grant Revell, and John Kregel analyze the results of a National Provider Survey on the growth of supported employment services (page 27).

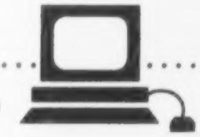
You will find inserted in this *Newsletter* the TASH annual conference brochure. The brochure contains the tentative conference agenda, along with an overview of session topics and TASH Tech workshops, as well as the registration form. We have already started to receive conference registrations — don't forget to send yours in soon!

Another upcoming noteworthy event is the University of New Hampshire - Institute on Disability/UAP's Equity and Excellence Conference. TASH is one of the co-sponsors of this school restructuring and inclusion conference, scheduled for October 1-3, 1997. Additional details, along with the list of keynote speakers, appear on page 19.

It is with deep sadness that we report the recent passing of Sandra Jensen. Beginning on page 8, we remember Sandra's courage and determination in winning her battle to become the first person with Down syndrome to undergo a heart and lung transplant.

Lastly, don't forget that it's TASH Executive Board election time again! Biographical information on this year's field of highly qualified candidates begins on page 21. Ballots must be postmarked by September 30, 1997.

— Priscilla Newton, Editor



WHOM DO I CONTACT??

- **For issues of policy, chapter or committee support or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on the conference, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For information on government affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:mroth@tash.org
- **For information on membership, permission and reprints, newsletter advertising, or publication/video sales, call:** Priscilla Newton, Director of Member Services, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the newsletter or to make a submission, call:** Priscilla Newton at (410) 828-TASH, Ext. 102.
- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230, e-mail: lgoetz@sfsu.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail: pnewton@tash.org

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I was totally shocked and devastated by the "Hot Fudge Sunday" article by David Hingsburger in the May 1997 TASH *Newsletter*. Many of us parents, individuals with disabilities, and advocates have killed ourselves to try to get inclusive recreation programs in our communities for decades. The TASH I used to know was one of the few groups that understood that "separate is inherently unequal" and Special Olympics — like special schools, special busses, special institutions and special anything else that is segregated – promotes exclusion. These segregated venues stereotype people, and do not encourage the sharing and friendships with typical folks that I thought inclusion was all about.

Special Olympics is the cultural epitome of the charity, pity and segregation model. The fact that it is so accepted and embedded in our culture makes it the more dangerous: Telephone solicitors raise millions for Special Olympics (and more millions for themselves); part of Tonya Harding's punishment for arranging the assault on Nancy Kerrigan was to donate $50,000 to Special Olympics; when two firemen in northern Kentucky "seized the roof" of the local high school and would not come down until the public donated $10,000 to Special Olympics, they were "heroes for such a worthy cause" and received national publicity!

The paradigm of exclusion and segregation is everywhere. The response from people around us is always "why would you want an inclusive program when your son could be with his own kind in Special Olympics?" This is the same comment we received when we tried to get our son into public school or onto the regular bus with his brother and neighbors.

I can just see Special Olympics distributing copies of the current TASH *Newsletter*! I think you need to make a public apology to the individuals and parents of TASH who have suffered greatly because they refused to tattoo "retarded" on their childrens' foreheads and participate in Special Olympics. At great personal expense and public humiliation, our family has tried to counteract the negative effects of Special Olympics in our community. It would have been much easier for our family to sell out and enroll our son in the many segregated Special Olympics' events. Instead, we honored the philosophy of inclusion - which I thought TASH shared - and had many fewer leisure opportunities for our son at much greater expense. We continually had to defend our choice to make him the "only person with disabilities" on the cross-country and track team, the "only one" to go to the school prom, the "lowest functioning" person to.... Meanwhile, the school and community provided cultural, monetary, and personnel support to Special Olympics, often on schools' and local business' time.

Last Saturday, Aaron was one of over 600 students who graduated from our local high school. Sure, he was the only one who wouldn't keep the graduation hat on his head (he was probably the only one who was comfortable), but what was so wonderful was when he walked up the aisle, he got a big round of applause. Twenty years ago, the neurologist told us, "Aaron will always be in special schools and they [are] SOOOOOO good for retarded children's self-esteem and [Aaron] will only suffer in a regular school."

If Mr. Hingsburger went to many institutions or segregated schools, he would be equally impressed with their spirit and self-esteem...but he would miss the point. "Success is defined not by what you achieve, but by the number of obstacles you overcome." The neurologist and Mr. Hingsburger are caught in the old paradigm. Their exclusionist attitudes are the views of the majority culture. But we can hope and work for inclusion because we live in a regular world, not a special world and I still believe separate is inherently unequal.

— Mary Ulrich
W. Chester, OH

TASH's publication of an article which references the impact of Special Olympics on some peoples' lives, points out to us that yes, many people with disabilities truly do have athletic abilities and do have the desire to compete in sports. The article also shows us the value of participation in competitive sports and, unfortunately, the limited opportunities. The transition to full inclusion in competitive sports is not complete by any means.

Special Olympics has begun to recognize the desire of athletes to participate in sports along side peers who do not have disabilities. Special Olympics is developing the Unified Sports program to move toward the integration of athletes with mental retardation into typical sports.

This article points out the need for TASH to take a very pro-active approach to advocating for access to typical sports for ALL people. TASH's efforts can be directed at ensuring that inclusive sport opportunities are available that do accommodate individuals with disabilities. The Leisure and Recreation Interest and Action Group will continue to work toward inclusive recreation for everyone.

— Cynthia Kay Burkhour
Jenison, MI
(Convener, TASH Leisure and
Recreation Interest and Action Group)

What one would define as appropriate recreational services for people with developmental disabilities has changed dramatically over the past 30 years. At the same time, the fundamental premise of the Special Olympics has not necessarily changed. In the May 1997 TASH *Newsletter*, David Hingsburger wrote that we need sport, social contacts, and media coverage for people with disabilities. Yes, but do we get them with the Special Olympics? Do we get positive examples? You need only look at some of the issues surrounding the Special Olympics to answer these questions:

Segregation: There is no way around it. The Special Olympics is a segregated event. You can only participate if you have a disability. It is as if there were signs saying "disabled only."

Lack of Functional Skill Acquisition: Many of the events are of limited functional value and do not prepare people for the criterion of ultimate

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functioning. And because teachers and others spend many hours practicing for these events, much precious teaching time is lost.

Age Inappropriate: The participants are often portrayed as children, although both children and adults compete. The denial of adult status and dignity reinforces the infantilization of adults with disabilities.

Lack of Normalization: In the Special Olympics, everyone wins. In real life, such is not always the case. Individuals with disabilities should be allowed the dignity of risk. The Special Olympics set up an artificial environment where the rules are not the same, yet everyone pretends they are.

Roles of Participants and Coaches: The coach is in the dominant role, and the athletes are in the subordinate role (less able, more dependent, and unequal). What is needed is reciprocity and equal status among people with and without disabilities in order to foster friendships and social networks. Activities in which the person with a disability is a co-participant with people without disabilities is also required. However, none of this occurs in the Special Olympics.

Image: With the Special Olympics we get a negative, self-fulfilling prophecy that evokes sympathy, pity, and/or stigma. Here are several examples from the media:

- Erma Brombeck wrote: "Suppose behind the vacant, empty eyes, the gold medal on the red, white, and blue ribbon dazzled them and meant something. Is it possible that the mouth that could not control saliva was willed by the brain to smile, but the muscles just couldn't do it?"

- The Los Angeles Times referred to participants as "Enchanted creatures" and "angels unaware."

- The Syracuse Herald-American said that it was difficult "deciding where the 'special' ends and the 'Olympics' begin," and an editorial in the same paper noted that Special Olympics volunteers learn that "the mentally retarded are 'great kids'".

Promotion of "Handicapism": This is the theory and set of practices that promote unequal and unjust treatment of people because of apparent or assumed physical or mental disability. Because Special Olympics is designed to serve only persons with disabilities, it focuses the public's attention on the disability rather than the person.

Role of Athletic Activities: Not everyone likes to participate in athletic activities. It may be easier to get friendships and social networks in non-athletic situations.

Lack of Empirically Verifiable Benefits for Special Olympics: It is surprising that there has been very little empirical evaluation of the Special Olympics. There are no data indicating that the Special Olympics provide quality of life outcomes such as friendships, social networks, community participation, and positive attitudes. However, there is data indicating that Special Olympics leads to reduced expectations and negative attitudes towards people with disabilities.

Financial Issues: Where does the money donated to the Special Olympics go? There are many troubling aspects of the finances of the Special Olympics. According to their IRS 1099 data, the Special Olympics had an income of $21,435,707 in 1994 and $28,887,391 in 1993. The Special Olympics has 5 officers making $90,000 a year or more (plus benefits), and 25 employees making $50,000 a year or more.

Sargent Shriver (CEO and Chairman of the Board) did not receive any compensation or benefits, but did receive $5,640 for the use of a company car. Edgar May (Chief Operating Officer) received $135,633 in compensation and $9,500 in benefits, plus $19,588 for the use of a company car and apartment. Robert S. Shriver, III (Director) received $130,000 in compensation and $18,800 in benefits for services provided in 1994 and 1995.

The Special Olympics paid $611,818 to Epsilon (Direct Mail Consultant); $552,983 to Meyer Associates (Telemarketing Consultant); $318,622 to Robinson, Lake, Sawyer, Miller (Public Awareness Firm);$292,763 to Kershner & Company (Public Awareness Campaign); and $134,458 to Cherry Joy Beysselance (Attorney).

American Institute of Philanthropy Rating for finances of the Special Olympics was a C (Satisfactory).

What is to be done? Hingsburger indicates that with the Special Olympics we get pride in sport, self, and purpose. These are not lifestyle outcomes around which we build services and supports.

So what do we do? Do we try to reform the Special Olympics? No, because the basic premise of the Special Olympics is wrong. It is based upon the idea that people with disabilities need segregated recreational activities. Special Olympics doesn't teach functional skills, and it doesn't allow persons with disabilities to function in normal society. We need to replace it with programs that teach functional skills in integrated recreational situations.

— Keith Storey
Concord, CA

Hooray for TASH for bringing us Dave Hingsburger's article about his actual experiences with Special Olympics. I have long been tired of people criticizing something they have not taken the time to experience. It had always reminded me of the critics of special education, community living or whatever we were trying to advocate for and the NIMBYs (not in my back yard) who fought us. As happened so often, once "they" got to know people with disabilities, they changed their attitude. How brave of TASH to print an account of one of our own. And now I can hold my head higher when I tell you the following.

In July 1995, for 5 summer days of 98° temperature and high humidity, my son (and many others) walked the difficult Yale Golf Course. For each of the first two days, he played 18 holes of qualifying rounds. For each of the next three days, he played 18 holes of competitive golf by PGA (Professional Golf Association) rules.

I didn't need to see Jonathan play 90 holes of golf to know that he was a well-trained athlete who had earned the right

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TASH CHAPTER
News & Views

BY DEBBIE GILMER, PRESIDENT, NEW ENGLAND CHAPTER

While it may not always appear to be the case, the Board of the TASH/New England Chapter has been very active, and many things are happening in our attempt to maintain focus, increase our visibility, and rejuvenate activity in New England. In addition to our quarterly meetings, the Board now has monthly teleconferences, and an e-mail network has been established.

Recently completed and upcoming projects and activities include:

National Conference

New England is honored, indeed, to be the host to the national TASH conference scheduled for December 10-13, 1997 in Boston. Make your plans now to attend! A number of New England TASH members are actively involved in planning conference activities, and we are keeping our membership posted on ways in which New Englanders can become involved.

The Chapter Board hopes the conference will energize New Englanders, provide opportunities for family members and direct support staff to attend, and showcase the wonderful things happening across our region.

New Officers and Board Members Elected

Last fall, a new slate of officers was elected. I was elected President, and Paula Agins from Rhode Island was elected Vice President. Secretary Cindy Politch from Massachusetts, and Treasurer Mike Shields of New Hampshire, were re-elected to those offices.

New Board members elected by state delegations include: David Hoff (Massachusetts), Susan Yuan (Vermont), James Piet (New Hampshire), and Don Trites (Maine).

State Contacts

To assure that timely information about the chapter is made available to interested individuals and organizations, a Board member representing each state in the region has agreed to serve as a point of contact:

These individuals are: Linda Rammler (CT), (860) 349-7083; Doreen McConaghy (RI), (401) 942-7050; Addie Comegys (MA), (508) 468-1484; Susan Yuan (VT), (802) 656-8166; Mike Shields (NH), (603) 528-3060; and Debbie Gilmer (ME), (207) 581-1263. State contacts have chapter and national membership information, and can assist in responding to New Englanders' inquiries for information and assistance.

Mini-Grants

For the last several years, the TASH-NE chapter has awarded small grants to individuals and families that have as their purpose the inclusion of children and adults into community activities. The process for reviewing this years' applicants is now complete. More than forty applications were received, and applications came from every New England state. Awards for 1997 were announced in May.

Spring Workshop

The chapter sponsored a successful workshop on self-determination, conducted by Don Shumway of the Robert Wood Johnson Foundation. The workshop was held at the Institute on Disability at the University of New Hampshire in Chelmsford, MA in March. More than 60 self-advocates, family members and providers participated.

The workshop was the first in a three part series, "Prying Loose the Power." The second part, designed by and for self-advocates, will be held in the Fall. Details will be available from TASH-NE Board members in the near future.

Legislation and Policy Issues

TASH-NE members and advocates in Massachusetts continue to struggle to pass legislation that would prohibit the use of aversives to control behavior and punish children and adults. Both TASH and TASH New England remain active in this effort. (See a related article on the use of aversive techniques in this issue of the TASH *Newsletter*, pages 3 and 5.)

In the meantime, it appears that children and adults residing at the Judge Rotenberg Center (formerly BRI) continue to receive electroshock treatments, have to earn their food each day, and are otherwise hurt and humiliated in the name of treatment. We are committed to ending these practices.

Education reform initiatives in all New England states - including School to Work and Goals 2000 - appear to be positively impacting inclusive education efforts. TASH-NE members have provided significant leadership regarding inclusive education in all states within the chapter.

Three states in the region were recently awarded grants from the Robert Wood Johnson Foundation to develop self-determination projects. These projects have the potential to positively influence both policy and community support practices by placing greater choice and control in the hands of individuals with disabilities and their family members.

Congratulations to Connecticut, Vermont, and Massachusetts, as they join New Hampshire in implementing self-determined supports!

Chapter Newsletter

While there are no plans at the present time to institute a regular chapter newsletter, we are interested in enhancing lines of communication and information sharing. We continue to welcome information from the membership, and will make every effort to disseminate it to the New England mailing list in a timely fashion.

If anyone has suggestions regarding more efficient and effective information sharing strategies, please let us know!

Have a happy and safe summer!

Information for the TASH Chapter News and Views column should be forwarded to: Bill Gorman, Editor-TASH Chapter News and Views, 1556 First Avenue, South Iowa City, Iowa 52240 or Linda Rammler, Chair, TASH Operating Committee, 6 Way Road, Suite 301, Middlefield, CT 06455.

SANDRA JENSEN

Transplant pioneer loses battle for life

On January 23, 1996, Sandra Jensen became the first person with Down syndrome to undergo a heart and lung transplant. She received international attention for her struggle to receive the transplant. Sandra demanded that hospitals view her as an individual in need of an organ transplant, not as an individual with a disability.

TASH had the great privilege to host Sandra as one of its keynote speakers at the 1996 annual conference in New Orleans last December. TASH, along with many others throughout the world, will be forever grateful for Sandra's courage, determination and perseverance.

We extend our deepest sympathy to the family and supporters of Sandra Jensen.

Sandra Jensen

Sandra Jensen, whose bid for a heart and lung transplant became a cause celebre for people with disabilities and their advocates, died May 23rd, 14 months after her landmark surgery.

Jensen, 36, died of complications from the drugs that she needed to stave off rejection of her replacement organs.

"My heart is broken. Sandra's death is a huge loss," said William Bronston, a physician who helped Jensen in her fight to become the first person with Down syndrome to undergo a successful tandem transplant.

The Sacramento woman was initially rejected by two hospitals as a candidate for the complex transplant because she had Down syndrome. But Jensen, a high school graduate who had worked in the past on behalf of people with disabilities, held a steady job and lived on her own for years, protested.

Her story stirred civil rights advocates and, amid intense pressure from activists, friends and relatives, the hospitals reconsidered. In January 1996, doctors at Stanford University Medical Center replaced Jensen's failing heart and lungs with the healthy organs of a teenage girl who had committed suicide.

> **"[Sandra's] biggest statement was, 'Treat me like an individual, not like a member of a particular group,' . . . She proved that every patient, regardless of disability, needs to be evaluated as an individual."**

After the operation, Jensen said she felt stronger than she had in years, and she tearfully thanked the strangers who had given her a second chance at life. "I can't say much about the donor," she said. "But I do want to say one thing to the family. Thank you."

Advocates hailed the surgery as a victory for disabled people nationwide, and praised Jensen as a pioneer.

She returned to Sacramento in July, on the same day that a bill inspired by her case became California law. The law prevents doctors and hospitals from denying access to life-saving transplants based on a person's disability.

That kind of discrimination is outlawed by the federal Americans with Disabilities Act, but Jensen nevertheless had to convince her doctors that she could handle the complicated medical regimen that follows transplants.

Jensen had suffered various complications since the transplant, but recently was enjoying relatively good health, said her cardiologist, Dr. Philip Bach. Then, she developed lymphoma, a common side effect of the drugs that suppressed her immune system and prevented her body from rejecting her transplanted organs.

She died following surgery to remove a brain tumor, he said. "This was a complication that can occur with anyone who has a transplant," said Bach. "I want to emphasize that it had nothing to do with her as a person, or as someone with Down syndrome."

During the 14 months since the surgery, Bach said, Jensen "never had one problem with not taking her medications or managing her care. She followed a complicated medical regimen beautifully. "Her biggest statement was, 'Treat me like an individual, not like a member of a particular group,'" Bach said. "She proved that every patient, regardless of disability, needs to be evaluated as an individual."

Bronston said no similar transplants have been performed on people with Down syndrome since Jensen's surgery. "From the day she was born, she was a fighter," said Jensen's father, Frank Jensen, who was at her side at Sutter General Hospital when her life-sustaining ventilating machine was turned off Friday. In an irreversible coma, she died about 15 minutes later. "She gave it all she had."

His daughter never regretted seeking a new heart and lungs and risking the medical complications that ultimately caused her death, he said. "It was a chance she wanted for a better life."

Jensen was born and raised in Sacramento and attended schools for children with disabilities until she was 15,

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Conversion from Facility-Based to Community-Based Employment Supports: Preliminary Results of a National Study

BY PAT ROGAN, SUSAN RINNE, AND MARY HELD

Over the past year, members of the Indiana Employment Initiative have been conducting a national research study of organizations undertaking the changeover, or conversion, process from facility- to community-based services and supports for individuals with disabilities. To date, 120 organizations have been identified as "converted" or "in conversion," including large and small agencies in urban and rural areas throughout the country.

A questionnaire was developed and mailed to identified organizations that included items related to the organization itself (e.g., types of services offered, number of people served, number of staff and their roles, nature of the physical facilities, and geographic location), and about the agency's conversion process (e.g., how they define conversion, how far along they are in the conversion process, the impetus for change, outcomes, barriers, successful strategies, stakeholder reactions, and impact on finances).

To date, 34 (28%) of the questionnaires have been completed and returned, so the information presented here is preliminary. This article focuses on findings related to major barriers to conversion, strategies for addressing these barriers, and what agencies would do differently.

Conversion Barriers and Strategies

The table to the right lists barriers in rank order, with the biggest barrier first,

CONVERSION BARRIERS AND STRATEGIES

Barriers	Strategies
Funding	Be proactive! Educate funders about your need to use existing dollars flexibly. Work to improve internal efficiency. Decentralize programs and flatten organizational structure. Seek grants, transitional funding, and other sources of revenues. Obtain technical support as needed, and be willing to take financial risks. Sell or lease the building and other "sunk" costs.
Negative attitudes of key stakeholders	Strong leadership is needed within the organization. Invest heavily in staff training and information dissemination about promising practices. Demonstrate and celebrate success. Involve key stakeholders from the start. Plan individually with people and family members. Support people to explore job and community options and parent-to-parent education. Support self-advocacy groups. Some staff may opt to leave the agency. Hire new staff who fully embrace the mission, vision, and values of the organization.
Regulations	Seek waivers from Vocational Rehabilitation and Medicaid. Advocate with others to change problematic regulations (e.g., state level task force, meetings with state level decision-makers, etc.).
Lack of Expertise	Learn how others have approached organizational change by bringing in outside "experts," attending conferences and workshops, reading publications, etc. Provide ongoing training and technical assistance for staff and other stakeholders to learn new skills and feel safe trying new roles.
Leadership	Leaders must be value-based and have a strong desire to change the organization. Leadership must be shared. Opportunities for staff to take leadership roles must be provided. Leaders need to increase accountability within the organization, promote forums for discussion and ongoing communication, and celebrate successes.
Full Day Supports	Design services and supports with each individual. If the person does not work full-time, determine where the person would like to spend time and with whom. All people do not need or want 6-7 hours of "programming" each day. Support people in need of attendant care to hire people from outside the agency.
Transportation	Use multiple options such as ride sharing, public buses, assistance from the state to fund private transportation, mobility training, cabs, and private vehicles.
SSA Disincentives	Work for changes in SSDI laws. Provide individuals and families with "user friendly" information.
Operating Dual Systems	If needed, secure transitional funding from Developmental Disabilities Planning Councils, Vocational Rehabilitation, and/or grants to help during the interim period prior to facility closure.

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CONVERSION FROM FACILITY-BASED TO COMMUNITY-BASED EMPLOYMENT SUPPORTS: PRELIMINARY RESULTS OF A NATIONAL STUDY

continued from page 9

and provides a summary of strategies to address each barrier.

Is There Anything You Would Do Differently?

When asked "Is there anything you would do differently?" organizations provided the following suggestions:

- **Avoid the words conversion, affirmative industry, and backfilling.**
- **Remain flexible in your approach, but continually reference your mission and values.**
- **Provide more outreach and in-services with individuals and their families.**
- **Provide more in-depth training of staff at the beginning.**
- **Less training, discussion, and philosophy wrangling.**
- **Take more time to plan.**
- **Work toward better communication across the agency.**
- **Do it faster! Complete it! Be clear about goals.**
- **Change more slowly than we did.**
- **Hire new staff with desired skills at the beginning of the process.**
- **Burn the building down! It's too easy to have people come and do widgets than to be creative.**
- **Don't get so stressed out!**
- **There is no perfect formula for a successful conversion.**
- **Better document changes over time (videotapes, photographs, interviews with people and families, consumer biographies, etc.)**
- **Establish Board and staff consensus.**
- **Stop backfilling sooner.**

To date, the National Conversion Study data has provided a wealth of interesting and helpful information. A final report will be written and disseminated at the completion of the study. For more information, please contact the authors.

Pat Rogan is an Associate Professor of Education at Indiana University and a Research Associate at the Institute for the Study of Developmental Disabilities, the University Affiliated Program of Indiana. Pat can be contacted at (317) 274-6801. Susan Rinne is Project Coordinator of the Indiana Employment Initiative. Mary Held is a doctoral candidate in Special Education.

MY COUNTRY

One-Hour Film on the Disability Rights Movement, Funded by the Department of Justice, Set to Air on Public Television Beginning in July

In 1939, a policy banning black performers stopped contralto Marian Anderson from singing at Constitution Hall. Fifty years later, Anderson's own nephew, symphony conductor James DePreist, who contracted polio as a young man, faced architectural barriers at Constitution Hall. It was more than half a century after Anderson was turned away that Constitution Hall was renovated to provide access to people with disabilities.

In a one-hour documentary entitled MY COUNTRY, James DePreist profiles three people with disabilities, whose lives have been shaped by the struggle for equal rights. Beginning in July and airing on public television through American Program Service, MY COUNTRY will examine the civil rights movement that has brought down barriers for over 49 million Americans. MY COUNTRY is a production of Access Video and Ward & Associates, funded by the Department of Justice, and presented to public television stations by Maryland Public Television.

MY COUNTRY profiles three people with disabilities: Kathy Martinez, a disability rights activist; Hughey Walker, a Vietnam veteran and the first African-American elected official in his South Carolina county; and T.J. Monroe, a People First activist.

In 1994, T.J. Monroe became the first person with mental retardation to serve on the President's Committee on Mental Retardation. Placed in an institution as a child, Monroe fought a long battle for independence from the state. Now, he travels the country speaking at conferences and teaching workshops, in addition to his job at a senior center. As Monroe tells audiences, "The bottom line is showing people that they are equal and they have rights just like everybody else."

Check television listings in July for the viewing time on your local public television stations.

Clinton Inks Assisted Suicide Bill

President Clinton recently signed a bill banning use of federal money to support physician-assisted suicide – a practice that he said is wrong.

"While I have deep sympathy for those who suffer greatly from incurable illness, I believe that to endorse assisted suicide would set us on a disturbing and, perhaps, dangerous path," Clinton said in a statement.

The narrowly focused measure bars the use of federal funds for assisted suicides, a practice already illegal under state statutes throughout the country. It does not address the broader issue of the constitutional "right to die," or the rights of doctors to help people end their lives.

The measure passed the Senate 99-0 after being approved by the House 398-16.

"This is appropriate legislation," Clinton said. "Over the years, I have clearly expressed my personal opposition to assisted suicide, and I continue to believe that assisted suicide is wrong."

TASH's Membership Operating Committee is seeking members!

TASH's newly-formed Membership Operating Committee seeks members to support the recruitment efforts of the organization. Members will be responsible for designing membership development programs, developing enhanced services and products, and integrating with TASH Board members, chapter representatives, members, and staff on membership issues.

If you are interested in utilizing your personal and professional talents as a TASH supporter to assist our efforts in this critically important task, please contact Priscilla Newton, e-mail: pnewton@tash.org or call 410/828-8274, ext. 102, or NancyWeiss, e-mail: nweiss@tash.org or call 410/828-8274, ext. 101.

Help us reach out to publicize the resources
TASH provides to an even greater number of people!

OPTIONS NEEDS OUR HELP!

Our colleagues at Options - Resource Center for Independent Living in East Grand Forks, Minnesota have been devastated by the recent flooding of the Red River.

Jay Johnson, director of Options, reports that the Center was inundated with five feet of water, which destroyed or damaged all of its furniture and much of its equipment. The basement still has two feet of water. (For a while, there was even a strong possibility that the building would be condemned.)

Even more tragic, the homes of four of the Center's employees - including Jay's - have also incurred major damage due to the flood waters.

A significant concern of Jay's and the other staff members of Options are the many area residents who rely on Options for assistance. Those folks have nowhere else to turn right now.

How can you help? By making whatever contribution you can afford. Financial assistance would go a long way in helping Jay and has staff restore their capacity to empower area residents with disabilities.

In addition, Jay has a special need for an architect or engineer who can give him advice on the Center's physical plant, including ways to avoid or reduce similar flood damage in the future.

Send donations, payable to Options, to:
Jay Johnson
Options Resource Center for
Independent Living
1010 Central Avenue, NE
East Grand Forks, MN 56721
(218) 773-6100 or 1-800-726-3692

FDR Memorial

As you may know, the bill to get a statue of FDR in a wheelchair included in the FDR Memorial has passed unanimously in the Senate. As Justin Dart said though, "a promise is not a statue," so it is necessary for us to be vigilant in our quest to see this campaign through to its conclusion.

There are two things you can do to get the legislation moving quickly in the House.

First, contact members of Congress on behalf of your organization, particularly Republicans, and those who chair relevant committees and subcommittees. Ask each of these Congressmen to co-sponsor the bill, and to move it quickly through the legislative process.

Second, ask the grassroots activists in the appropriate districts do the same. Contact the office of Congressman James Hansen of Utah, Chair of the Subcommittee on National Parks, Forests, and Lands:

The Honorable James V. Hansen
2466 Rayburn HOB, Washington, DC 20515
Telephone: (202) 225-0453, Fax: (202) 225-5857

Contact the office of Congressman Don Young, Chair of the Resource Committee:

The Honorable Don Young
2111 RHOB, Washington, D.C. 20515
Telephone: (202) 225-5765, Fax: (202) 225-0425

House Passes HR 1385:
"Employment, Training and Literacy Enhancement Act of 1997"

BY TONY YOUNG, POLICY ANALYST, UNITED CEREBRAL PALSY ASSOCIATIONS

Last month, the House overwhelmingly passed HR 1385. There was little controversy in contrast to the passage of the CAREERS Act almost two years ago. Congressman Buck McKeon (R-CA) introduced a package of amendments that addressed the areas that were unresolved in subcommittee and committee.

These changes included:

- inclusion of changes to Sec. 508 to improve use of assistive technology
- "individual plan for employment" replaces "individual written rehabilitation plan"
- improvements in due process hearings
- added language to promote self-employment and small business development as employment outcomes
- improved language for informed choice
- an expected amendment by Congressman Mark Souder (R-IN) to change the definition of "competitive employment," was not made

The bill reauthorizes the Rehabilitation Act for 3 years. Congressman William Goodling (R-PA), Chair of the House Education and Workforce Committee, said that the changes to the Rehabilitation Act were an interim step to allow the 106th Congress to do a more comprehensive review of rehabilitation programs. As of the time this issue went to press, the bill was scheduled to go before the Senate, where they plan to consider separately the job training provisions and the Rehabilitation Act.

The Senate Labor and Human Resources Committee plans to take a comprehensive look at the Rehabilitation Act, and will probably hold hearings in July or August.

Pizza Hut® **A Corporate Initiative to Employ 2,500**

Pizza Hut has set a 1997 goal to employ 2,500 vocational rehabilitation clients.

Integrated Resources Institute (IRI), a non-profit corporation, has assisted Pizza Hut with the **Jobs Plus** ™ initiative for persons with disabilities, which has resulted in over 17,000 job placements since 1989.

IRI will facilitate your job development efforts with local Pizza Huts. To access this free assistance from IRI, call us toll free at:

(800) 704-5293

Why Are We Reinstitutionalizing People During The Day?

FLEXIBLE DAY SERVICES AND PROGRAMMING WITHOUT WALLS MAY BE FEASIBLE ALTERNATIVES

BY LESLIE L. WILSON, M.S.

The Koi Phenomenon

Last year my husband came home and dug a large hole in our backyard. Before long, the hole took shape. It turned out to be a koi pond. He transferred the koi (Japanese carp or gold fish) from our daughter's small tank into the pond and one year later, the koi were twice their original size.

I learned that the size of the koi is in direct relationship to the size of its surroundings. If you keep a koi in a small fish bowl, it will only grow to be two or three inches long. Place the koi in an aquarium, and it will reach six to 10 inches. Put it in a large pond and it may get as long as a foot and a half. When placed in a huge lake where it can really stretch out, it has the potential to grow to three feet.

A comparable analogy can be made about the growth and development of all humans. **Our growth is determined by the size of our world. It's not so much the dimensions of that world, but the mental, emotional, spiritual, and physical opportunities we are exposed to.** (Glenn Van Ekeren, Speaker's Sourcebook II, Prentice Hall.)

Over the past 25 years, the koi phenomenon among humans has been supported by research which has followed people with developmental disabilities who have moved from isolated, segregated institutions to community-based homes. This research has shown that almost everyone who moved to a small home in the community gained adaptive behavior skills. In some cases, those who gained the most were persons with the most challenging disabilities.

Take the findings of the *Pennhurst Longitudinal Study*, for example. The study annually tracks individuals who moved to homes in the community from Pennhurst, a segregated, state institution in southeastern Pennsylvania, closed under court order during the 1980's. Pennhurst class members who were labeled profoundly mentally retarded had a 34 percent improvement in self-care skills after movement to the community, as compared to a 14 percent gain for their peers with mild mental retardation. (*Selected Findings from Two Decades of Research on Community Versus Institutional Living*, James Conroy, Ph.D., The Center for Outcome Analysis, 1996.)

We also know from the tracking of Oklahoma's service recipients with developmental disabilities (n=1,346) that persons living in homes with fewer than seven people experience significantly more growth on the adaptive behavior scale than those living in homes with seven or more people. (Oklahoma State University Quality Assurance Project, 1996)

The conclusion from the data is that no matter how challenging the disability, there is growth when people are moved to the community in small groups and have new and varied experiences.

The Reinstitutionalization of Persons with Developmental Disabilities During Weekdays

Why, then, have we spent millions moving people to the community to return them to segregated centers during the day, where up to 100 people or more with disabilities are congregated? No matter how challenging their disabilities, these individuals have the proven potential to grow and develop because the dimensions of their world have expanded. During the majority of their wakeful hours of the week, we return them to conditions similar to those they left when they exited the institutions. The only difference between many of the segregated day programs and institution day rooms is the physical size — the institution day rooms were often larger.

Just over one percent of Pennhurst class members and 17 percent of Connecticut's Mansfield class members are working in the community. (*The Hissom Outcomes Study: A Report of Six Years of Movement into Supported Living*, James Conroy, Ph.D., The Center for Outcome Analysis, 1995. Hissom was a state institution for persons with developmental disabilities closed under federal court order in 1994.) The great majority of these class members are segregated in center-based programs on weekdays. In Michigan, almost every Kope class member attends a segregated day program. These are the disappointing aspects of otherwise successful deinstitutionalization efforts.

Impressively, over 50 percent of Oklahoma's Hissom class members are working via the supported employment program; conversely, 23 percent spend their weekdays in segregated centers with others who have disabilities. (Based on Fourth Quarter Statistics, Oklahoma Department of Human Services' Developmental Disabilities Services Division, June 1996.)

The problem is pervasive. The 1990 National Consumer Survey, which tracked 8,798 adults with developmental disabilities, found that 81.5 percent of these individuals were in some type of segregated, center-based program. A mere 7.1 percent were in supported employment.

The Flaws of Segregated Day Services

We know from research that one of the hardest things for persons with cognitive disabilities is the transfer of knowledge. And yet, we spend hours teaching people skills in

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center-based programs that they will have to relearn if they ever have the opportunity to replicate them in the outside world.

Take the example of a day program that constructed an entire city block in the basement to teach participants community survival skills, like crossing the street. After everyone was *ready* to move to the actual street, the staff discovered they had done more harm than good. Cardboard buses on pulleys can be knocked over if you happen to make a mistake and walk in front of one. But a real bus, moving at its normal speed, can kill you if you walk in front of it. The staff then realized that the only way to teach survival skills was in the community, on real streets.

Functional learning is almost nonexistent in center-based programs and, in some states, there is a pervasive use of toys. Staff are so frustrated by their attempts to find meaningful programming, that they have turned to toys to give adults something to do during the time they spend in the center. Instead of teaching these individuals to purchase a soda from a vending machine by placing quarters in the slot, or learning to identify the men's room from the women's room in a restaurant - skills you can use everyday - individuals in center-based programs are learning how to place pegs in holes over and over again, or learning to tie their shoes, even though Velcro fasteners are readily available. When the people served refuse to participate in these useless activities, staff assume they aren't capable.

A prime example of an unproductive activity in a day center is that of a man who was supposedly *learning* color discrimination. He had a bucket of golf tees in red, green and white. He spilled the tees on the table, and impeccably separated the colored tees in three different piles. When an observer asked what happened next, since it was obvious he already knew these colors, the staff explained that he just began the task over again.

The worst day programs offer nothing. Participants and staff are idle for hours. At best, the personal hygiene and dietary needs of the individuals are met, and those with physical disabilities are periodically repositioned.

Center-based programs offer few opportunities for integration. Participants rarely spend time with people who do not have a disability, or who are not paid to work with them. Functional skill development, jobs and/or meaningful activities are the exceptions, not the rule.

The Alternatives May Be Programming Without Walls or Flexible Day Services

What is the alternative? Thirty hours of competitive or supported work per week for every person served is not always the answer. Those states that have attempted such a lofty goal have been disappointed by the results. Oklahoma is a classic case.

Just over 50 percent of the Hissom class is in the supported employment program, a tremendous outcome. The remaining class members have fallen through the service system cracks and are at home, or in some type of center-based program, despite efforts to get everyone into a paid or volunteer job 30 hours per week. In part, this happened because there was so much pressure, in the absence of alternatives, to get everyone working.

The pressure on the service system was appropriate. This force, coupled with the skills and commitment of consumers, advocates, the Homeward Bound Review Panel, the federal court, the plaintiffs' attorneys, the Oklahoma Department of Human Services' Developmental Disabilities Services Division, Department of Rehabilitation Services and the vocational providers, was responsible for creating the remarkable outcome of so many class members working in paid jobs.

But, after several years, it became apparent that it was time for a mid-course correction. In some cases, vocational providers were inexperienced or ineffective in serving persons with the most challenging disabilities; in others, the providers became frustrated because they found that not everyone wanted, or had the stamina, to work a 30 hour week. Some providers refused to serve individuals who were not sure what they wanted to do, and/or had the most challenging disabilities. For folks denied supported employment services, the alternatives were to go unserved or attend a segregated center during the week.

Other states have experienced similar difficulties. According to a report titled *Job Path: Shifting The Focus Beyond Just Work,* published by Syracuse University's Center on Human Policy (Hulgin and Searl, 1996), **"The development of alternatives to traditional day services is one of the greatest challenges facing organizations that support people with severe developmental disabilities today.** Efforts to support community integration have generally been limited to people who can hold typical jobs, with minimal or short term assistance. Few agencies have successfully developed services for people with whom it is difficult to determine their interests and choices, and who need intensive long term assistance."

In reviewing a program offered by Job Path, a New York provider, Syracuse University researchers discovered that for individuals with the most challenging disabilities, there has to be a focus beyond work. Effective services, they say, require consideration of an individual's entire life and coordination of all services offered.

A Job Path spokesperson said the goal is not to fill up a person's daytime hours with pre-established activities. Rather, staff investigate opportunities based on people's interests in their own neighborhoods. "We don't really have a set of established relationships and resources that we always go back to again and again," reported Job Path. "Each new person gets a brand new set of resources that we try to develop."

Job Path has found that these opportunities take time to develop, and the approach requires flexibility. They say that most people they serve are not headed toward full time jobs, and it is usually quite a while before their days are filled with meaningful activities. Job Path staff cite the example of a gentleman for whom it took nearly two years to develop opportunities. Today, he is working part-time, going to the library and planning to join a local gym. During the process of developing these situations, he attended the day center on a part-time basis.

During Oklahoma's mid-course correction, **decision-makers took a hard look at the day services offered, and determined the need for a flexible service system that addresses *individualized, meaningful, integrated activities*** during weekdays that may include paid work. For one person, that may mean 30 hours or more of paid work. For another, it may be a

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part-time paid and/or volunteer job, an integrated swimming program, and an integrated class.

Since the optimum service will always be supported employment, with as many hours as possible of paid work, the flexible day services have built in safeguards. Individual cases, referred by teams, will be reviewed by the funding source's trained staff to assure that the alternatives are appropriate. For some individuals with the most challenging disabilities, the alternative day services will be labeled Programming Without Walls. This program will provide many opportunities for integration, with minimal vocational services.

An example of Oklahoma's initial success with flexible day services is a young woman we'll call Donna. Donna was isolated in a segregated day program 30 hours a week because staff said she acted inappropriately, and had multiple disabilities that made it impossible for her to work or spend time in the community. The excitement of being out, they said, encouraged her to scream even more than she did in the center and would eventually damage her vocal chords. Today, this same woman has a brand new wardrobe and goes to the local YMCA for an integrated aquatics exercise class three days a week. She is well liked by the other swimmers and has perfected her aim when splashing: the ladies now wear shower caps to protect their coiffures when Donna is in the pool. Donna also goes out to lunch three days a week at a local restaurant where they have developed a menu for her and others who have diabetes. Donna helped them test the menu. She also participates in several volunteer activities, while staff work to find her a part-time, paid job. Donna rarely screams these days, and will soon have a low-tech communication device which will enhance her ability to appropriately communicate.

Programming Without Walls and flexible day services will be further tested in Oklahoma this year through the implementation of statewide pilot projects. For people who presently attend day programs, the center will be used as a base for repositioning or other needs during the day. For those who do not have a day program, their homes will be the base. Day center and residential staff will be trained and mentored to develop meaningful activities for the people they serve in their own neighborhoods and communities on weekdays. The activities will depend on the individual and his/her family's/guardian's values, but will offer opportunities for integration, pleasure, and skill development. Paid work and volunteerism, in accordance with Department of Labor Wage and Hour rules, will be high on the suggested list of activities.

To guide individuals and their teams in the development of appropriate day services, Oklahoma's Developmental Disabilities Services Division developed a tool titled the *Criteria for Optimum Individualized Vocational/Day Service.* This form encourages consumers and their teams to pick a minimum of five value categories from a list of 18 possible choices, including *"other."* The values include such things as *"more effective communication"* and *"ability to work in a variety of employment opportunities."* After the value categories are chosen, the consumer and his/her team select consistent day service options. For example, if one of a consumer's values is *"more financial independence, ability to purchase with own money,"* an appropriate service option would be paid integrated work. Under paid integrated work there are six services. If this person's values also include *"choosing a schedule that meets personal preferences and needs,"* an "individual placement" would be the type of paid work selected.

As for the cost of flexible day services and the Programming Without Walls model, there should be no increase; spending should remain static, on average, by reallocating federal waiver and state dollars. Presently, some states are paying between $50-70 per day, per person, for day program services. On average, that is $10 per hour, based on 30 hours of service per week. If the individual's home is used as the base for the Programming Without Walls service, there may be a slight savings in some states, since the administrative overhead of the day program would be eliminated.

A recent study in Virginia found the state was spending, on average, $4,200 to place someone in competitive employment, with support, as compared to an annual cost of $7,400 to keep an individual in a day program or workshop. More than $25 million was spent in 1994 on day programs, while only $11 million was spent to help people enter real work. Segregated day services in Virginia appear to be more expensive than community-based, integrated options. *(Supported Employment Services Save Dollars and Make Good Sense,* Paul Wehman, "The Advance," Association for Persons in Supported Employment, Vol. 7, No. 1, April 1996.)

Conclusion

The availability of quality supported employment services to persons with developmental disabilities in this country must be expanded. Supported employment is perhaps the most integrated, community service offered today. It promotes independence - the goal of all services offered to individuals with developmental disabilities.

Funding sources, advocates and providers need to also look at alternatives. It should not be all or nothing: a paid job or a center-based program. In such a community service system, individuals are forced to fit what is offered, as opposed to the development of individualized day services which meet their values, needs and desires. Flexibility in the delivery of day services to persons with developmental disabilities is vital, and Programming Without Walls and flexible day services may be workable solutions.

As Marc Gold told us more than 20 years ago when he proved that persons labeled "unteachable" could learn functional and marketable skills, we need to "*try another way.*"

President of Wilson Resources, Inc., Ms. Wilson is presently working with the Oklahoma Department of Human Services' DD Services Division to expand the employment and integrated day service opportunities of persons with the most challenging developmental disabilities. She was formerly assistant executive director of the Arc-Pennsylvania during the Pennhurst litigation and, from 1994-96, served with the Michigan Department of Community Health's Kope Advisory Group, established to assure the quality of services for class members with disabilities of the Kope v. Watkins lawsuit.

Ms. Wilson can be contacted at 904/656-5678 (voice and fax) or Wilsonwear @aol.com (e-mail).

A CHANCE TO BE MADE WHOLE:

People First Members Work to Tear Down Institution Walls

BY PEOPLE FIRST OF TENNESSEE — 1997

Fighting for Freedom is Hard Work

People First of Tennessee has worked hard to make some big changes for people who now live in institutions. Because they fought in court on behalf of institutionalized people, the state has agreed that people who now live in four institutions will get the services they need to move into their communities.

One way that People First members helped to win this victory was by acting as "next friends" for People First members who live in institutions. A "next friend" is somebody who gets a U.S. federal judge's attention for people who need the judge to protect their rights but cannot speak for themselves, and have no family willing or able to speak up for them.

On December 14, 1996, People First members and advisors met at the state People First office to talk about what they had learned about reaching out and being friends to people who still live in institutions. This was done for three reasons:

- because they want to continue to support people as they move out of institutions;
- so that other members of Tennessee People First who want to be friends for people in institutions can learn from them;
- so that members of self-advocacy organizations in other states who are working to close institutions can learn from them.

The ideas and experiences in this article come from a booklet of people's own words. John O'Brien listened to the meeting and kept notes on big charts. He checked his notes by reading them back to make sure that he got what people said. He organized people's ideas into the booklet. Then People First members and advisors checked the booklet, made corrections, and added more ideas and stories.

A Good Friday Visit

(Ruthie Beckwith, Staff Advisor with People First of Tennessee, describes the visit she made to a People First member.)

It was Good Friday at the institution. Afternoon cartoons were blaring from the television in the "living room" of one of the cottages where I sat observing Deborah, one of our People First members. Four staff members watched me sullenly as they sat in chairs along the wall. I had positioned myself across the room from Deborah after re-entering the building following a dispute over whether I could visit her.

For five years, Deborah's sister (her legal guardian) had opposed any contact between her and People First. This time, armed with a federal court decision, I was determined to visit. When I first arrived, Deborah and I moved into the dining room to talk. I wrote questions on a tablet because she has trouble hearing. I asked her how she liked her job at the workshop in town. She started telling me about problems with her paycheck and described the types of contract work she did.

Less than five minutes into this quiet exchange we were interrupted by three staff members in quick succession, each challenging my visit. With each challenge, I explained the court's decision. After the third challenge, I was invited to see the supervisor, who was anxiously packing up to go home as it was a state holiday. The supervisor, in turn, had me talk on the phone to the administrator on duty who, realizing the legitimacy of my request, passed approval back down the chain of command.

However, by the time we had resolved the dispute, Deborah had also gotten the "message" and had withdrawn back into herself. So, on Good Friday I watched as she sat in her wheelchair talking to a small Teddy bear she clutched in her hand. "Don't worry, Cassandra," Deborah said to the bear, "I'll make sure you get some Easter eggs. We'll look for some in the parking lot. There might be some in the parking lot. Don't worry. ..."

I wrote Deborah another note as I prepared to leave. I thanked her for taking time to talk to me and wished her a Happy Easter. She took the note and read it. She shook her head slowly and then set it gently on the table beside her.

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Not knowing anything else I could do, I picked up my backpack and headed out to meet my ride.

I walked across the grounds in the brisk spring air filled with anger and frustration. Three years after a major court ruling against the institution, little had changed. I visited six people that day, all of whom were still living out their lives on an island of isolation and hopelessness.

Clover Bottom Freedom Train Song

Get on board the freedom train is what I want to do,
tell this institution that my days here are through,
find a home and get a job in the community-
don't you think there's room enough for you and me?

Many years have come and gone since I've been in this place
waiting for an opening to join the human race,
three square meals are not enough to feed my lonely soul-
won't you give me one more chance to be made whole?

The days go by, each one's the same, no end to it in sight,
I try to keep my dignity and go on with the fight
to gain my liberation from this cold and heartless state,
can't you tell it's getting hard for me to wait?

I hear about the outside world and its opportunities,
I hear the whistle blowing for others just like me,
it's my turn now to get on board--I'm never looking back,
that freedom train is rolling down the track.

Get on board that Clover Bottom Freedom Train!

Get on board that Clover Bottom Freedom Train!

— Ruthie-Marie Beckwith, December 22, 1995

People Who Live in Institutions Need Friends

People who live in institutions and people who are moving out of institutions need someone who will:

- listen carefully to find out: their hopes and what they want to get out of life; their concerns, worries, and troubles; what help they know they need;
- talk with them about: their rights and how People First can help them get respect for their rights; what the judge says has to happen when they move out of the institution; the ways other people with disabilities are living with dignity in their communities;
- help out with problem solving by: sharing experiences and information and asking questions; encouraging them to keep working on important things, one day at a time;
- support them when their plans for moving out of the institution are made so that the plans make sense for them;
- advocate by: keeping an eye out to be sure that people stay safe; speaking up when things are not right and their voice isn't heard; getting help from People First when the institution doesn't do what's right; helping them to tell the judge why the institution won't follow the judge's order.

In one word, people need friends who will be there for them so they know that they are: not alone; not crazy to hope for better things; not bad to speak up for their rights and work for what they want from life. Friends who will show them there are people in the community who will be on their side; have been in their shoes and are making their lives better; will be friends after they move out; want to help solve real problems; need them to join in to make changes so that everybody's rights are respected.

Institutions Put Walls Between Friends

Institutions try to keep us away from each other by keeping the doors closed between us. The institution has:

- kept us from coming in to visit a friend;
- told us we have to leave and have no right to be there;
- made our friends disappear by moving them and telling us that they will not say where our friend has moved because of confidentiality;
- kept a person who wants to come from attending People First meetings because she has been moved from a building where staff take people out, to a building where staff don't take people out. (The people in the second building are older. In that institution, people lose the right to go out just because they have more birthdays.)
- kept people from getting mail about People First;
- kept people from making or getting phone calls between friends.

Sometimes the institution even separates people inside the institution who are friends. Many people have lost contact with their families because the institution makes it hard for them to stay in touch. When we do get to be with people, the institution still tries to be in control. They try to tell us when we can see our friends and for how long (even during free time). They try to tell us where we can see our friends. They say they have to be present because if they are not we will confuse, upset, or manipulate our friends.

Staff who bring people to People First meetings sometimes try to keep the wall around the people right at the meeting by:

- making all the people they brought sit together with them;

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- telling people not to talk to other members;
- listening in when people try to have a private conversation;
- interrupting people when they talk.

One of the best ways the institution has of trying to control people is to just ignore them. Some of us have made call after call to set ways for our friends to join People First meetings. The institution just doesn't call back. If they do call back, they say they can't do anything now but they'll call back later and then they don't call back later. If they do agree to do something, they just don't do it and then don't call back when you want to ask why they didn't do what they said they would.

Another way the institution controls people is to lie about what happens to people. A People First member got bruises from the way staff handled her, other members saw the bruises and heard how it happened. But the staff said it didn't happen. All the way up the line supervisors said it didn't happen. We have even heard staff people lie about things we know happened when they are under oath to tell the truth. When the institution won't even admit that there is a problem, it is very hard to work on a solution.

Mostly, the people who keep the walls up stay pretty cool and act like they are just doing their job. But sometimes the wallkeepers get really angry at us right out loud and say things like:

- "How dare you interfere! This is none of your business!"
- "You don't know what I have been through and how much hurt you are causing me!"
- "You are ignorant! You just don't know anything."
- "Get out of here!"

Often it is people's family members who say things like this to us. We think this is because the institution wants to turn people who care about the people inside the walls against each other. We don't want to hurt anybody, we just want to be sure that people get what they deserve.

What We Can Do to Get Through the Walls

When the institution tries to separate us from our friends we can:

- be firm, but not hateful, back at the staff people in the way;
- tell the staff people in the way that it is right for people to have friends and belong to People First if they want to;
- ask the staff people in the way to step aside so we can see and join with our friends;
- make it clear that we have no intention to upset or confuse people, we just want to see our friends, and get to know them, do things with them, and make sure their rights are respected.

Sometimes a staff person just will not let us see our friends and will not be moved. It's a good idea to let the People First office know about this. It may be something that can be settled with the institution. It may even be something that will need to be settled by the judge.

The institution walls are so strong because:

- lots of people think that people with disabilities can't do anything and will get hurt or in trouble if the institution does not control them;
- lots of people don't believe that people with disabilities have the same rights as anybody else;
- people in charge of the system don't want to take responsibility for making the kinds of big changes that it will take to make the kind of community services that respect people's rights;
- some staff people are scared because their wages and their careers are all tied up with the institution;
- some family members (and some staff people) just don't believe that there is any place but the institution that people can get the help they need;
- many of the services in the communities have been weak and have sent people back to the institution instead of figuring out how to help them better.

It is good to know what makes the institution strong. When we know what makes the institution walls strong, we can do a better job of tearing them down. Everybody needs friends who will work together to tear down the walls.

For a complete copy of the booklet, *A Chance to be Made Whole: People First Members Being Friends to Tear Down Institution Walls*, write to Rachael Zubal, Center on Human Policy, Syracuse University, 805 South Crouse Avenue, Syracuse, NY 13244-2280

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School Restructuring and Inclusion: Equity and Excellence for All

An Invitation to all TASH MEMBERS

Many TASH members are involved with elementary, middle, and high schools that are engaged in systemic school reform efforts. Many of these schools are examining their practices in relation to: assessment, grading, and diplomas; tracking and heterogeneous grouping; curriculum design and instruction; and school-community partnerships. As advocates for students with disabilities, we find ourselves working hard to make certain that all students, including those with severe disabilities, are an integral part of these systemic school reform initiatives. However, we are often frustrated by school practices, policies, and personnel that reflect the belief that "ninety percent of the student population is the whole school - or close enough" (Shapiro-Barnard, et al., 1996).

To bring students with disabilities more fully into the national school reform conversation, the Institute on Disability/UAP at the University of New Hampshire is sponsoring the second annual

School Restructuring and Inclusion: Equity and Excellence for All Conference

The audience for this conference will be school teams interested in gaining information, skills, and strategies on how to include students with disabilities in systemic school reform efforts.

The Equity and Excellence Conference broadens conversations about curriculum and instruction, school climate, standards-based reform, social justice, and sustainable change to include *all* students. It will offer participants provocative and challenging keynote presentations, as well as intensive learning strands run by leaders in the fields of inclusion and school restructuring. Keynote presentations will be given by:

- **ALFIE KOHN**, author of *No Contest: The Case Against Competition and Punished by Rewards*, who challenges broadly held assumptions about grading, rewards and punishment, behavior management, and competition in education.
- **ROBERT MACKIN**, principal of Souhegan High School, in inclusive high school and a member of the Coalition of Essential Schools. Mackin speaks from experience about the importance of school climate, building a community of learners, and involving teachers in reflective inquiry and sustainable change.
- **NORMAN KUNC**, a family therapist and an educational consultant in the areas of inclusion, self-determination, and the dangers of benevolence, who believes schools need to create a sense of belonging for all students.

■

How can schools be restructured so that the inclusion of each and every student in the mainstream of regular education is a necessary condition for the achievement of excellence by all?

■

This conference is an opportunity to support the growing number of schools interested in achieving equity and excellence for all students. As TASH members and advocates, we recognize that inclusion will not thrive unless schools change their values and restructure their curriculum and related organizational systems. To this end, we encourage you to support your school to assemble a team of educators and parents to attend this important conference.

For additional information, please call Deb Wilkinson, 603-228-2084. Due to limited space, registration will be via an application process, and teams will be given first preference.

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School Restructuring and Inclusion: Equity and Excellence for All

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The Equity and Excellence Conference will be held October 1-3, 1997 in the historic seaport of Portsmouth, New Hampshire. It is sponsored by the University of New Hampshire's Institute on Disability/UAP and co-sponsored by TASH; the Consortium on Inclusive Schooling Practices; PEAK Parent Center; Inclusion Press International; New Hampshire Association for Supervision and Curriculum Development; Center for Professional Educational Partnerships at Plymouth State College; New Hampshire Department of Education; and, the Institute on Emotional Disabilities at Keene State College. The Institute on Disability/UAP is located at the University of New Hampshire, 10 Ferry Street, Unit #14, Concord, New Hampshire, 03301. Our e-mail address is <institute.disability@unh.edu> and our web site is <http://iod.unh.edu>

Shapiro-Barnard, S., Tashie, C., Martin, J., Malloy, J., Schuh, M., Piet, J., Lichtenstein, S., and Nisbet, J. (1996). Petroglyphs: The writing on the wall. Durham, NH: Institute on Disability/UAP, University of New Hampshire.

Transplant pioneer loses battle for life

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when she enrolled at Rio Americano High School. She graduated in 1981 and later worked busing tables at the cafeteria in the state Capitol.

She was a past president of Capitol People First, an advocacy group for people with disabilities, and frequently spoke to school groups and others.

Her brother Mark said he will remember his sister's upbeat attitude, her determination and her drive to help others. "She was so successful in her own way," he said. "She was so active. She was always doing speeches and going to conferences. She had Down syndrome, but all her friends said she had 'Up syndrome.'"

Bronston, who has campaigned to increase awareness of the need for donor organs and to end medical discrimination against the disabled, said Jensen "is a memento of quality of life for people with disabilities, and all people."

"We must keep up the fight," he said. "Sandra's death, and her life, must not be wasted."

Jensen is survived by parents and stepparents, Kay and Anthony DeMaio, of Oregon and Frank and Bonnie Jensen of Sacramento; brothers Mark of Sacramento and Keith of Fremont; and four nieces and nephews.

Funeral services were held on Wednesday, May 28.

The family has requested that any remembrances be sent to Stanford University Medical Center Falk Cardiovascular Research Center, 300 Pasteur Drive, Palo Alto, CA 94305.

The Sacramento Bee, 1997. Reprinted with permission.

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The 7th Annual
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Tools for Change

NOVEMBER 5-8, 1997

at the Primrose Hotel in downtown Toronto

Hosted by Marsha Forest and Jack Pearpoint, this unique workshop is a four day hands-on course to practice Circles, MAPS, PATH, solution Circles, Graphic Recording and process Facilitation. Teams are welcome, however enrollment is limited. Tuition cost is $500. To reserve space, send a deposit or Purchase Order to the address below. Checks should be payable to Pearpoint Forest Services.

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or visit our Web Page: http://inclusion.com

The 1997 Executive Board ELECTION

BUILDING TASH LEADERSHIP

Now is the time for you to decide who will help provide critical leadership in TASH's social justice movement for people with disabilities. Many impotant issues and challenges face us - your participation as a voting member of TASH counts more than ever.

Five of the 16 seats on the TASH Executive Board will be re-seated at the December 1997 TASH Conference in Boston. The individuals who appear on this year's slate have made significant contributions in the lives of individuals with disabilities and have demonstrated leadership in the disabilities movement.

Your vote is critical. Please use the postage-paid, self-mailing ballot provided on page 25, or clearly write "ballot" on the envelope you use. Ballots must be received at the TASH office by September 30, 1997. Please use ink and vote for five candidates. Voting for more than 5 nominees will invalidate your vote.

THE FOLLOWING ARE THE NOMINEES FOR THE TASH EXECUTIVE BOARD OF DIRECTORS

MICHAEL AUBERGER

Mike Auberger is Co-Director of Atlantis Community, Inc., the second oldest Independent Living Center in the United States; is co-founder of ADAPT, a national disability rights organization which addresses the inequities in the system for people with disabilities; and has served on the TASH Executive Board of Directors since Fall 1994.

Mike has a 23-year track record of advocating for people with disabilities, particularly in the area of making transportation accessible to all people. He participated in the writing of the Americans with Disabilities Act (ADA) and now, as part of ADAPT, is spearheading the personal assistance fight. He is also regularly involved in IEP and education issues for children with disabilities.

"In my different roles," says Mike, "I am required to be both the conservative and the radical. I believe I can assist TASH to grow and become a greater agent for change and have a larger part in the disability community."

BETH BRENNAN

"I am excited and honored to be nominated as a candidate to the TASH Executive Board. When I came to my first TASH conference several years ago, I was working as an aide with young adults in a segregated setting in Ohio. I was not there because I adhered to a philosophy that supported the setting. I was there because I was committed to the young people that I knew there whose families believed that setting to be the best place for their children. I soon recognized family advocacy as key to the inclusion of children with severe disabilities into their neighborhood schools. I also soon realized that the early information and opportunities that families receive frame their ideas and philosophies about what is best for their children." As Beth's awareness grew, so did her dedication to the goal of furthering her education and her ability to create a change. Currently, Beth finds herself in a variety of positions, each offering the opportunity to make the most of what she has learned from her experiences in the field. Beth is currently co-chair of the TASH Early Childhood Interest and Action Group. As the Early Childhood I & A Group plans for the TASH 1997 Conference, it is focusing on early advocacy and issues specific to the inclusion of very young children with significant disabilities in natural community and school settings. Beth is the Research Coordinator for the San Francisco State University site of the Early Childhood Research Institute on Inclusion (ECRII), a

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multi-university research institute whose primary purpose is to study the inclusion of young children with disabilities in typical preschool, child care and community settings. She is also currently a doctoral candidate at Kent State University. Beth's dissertation focus flows from her ties with extended members of the families that she knew through her work in the Early Intervention system in Ohio. Beth's specific interest is in increasing information and support services to grandparents of children with disabilities. Beth has also had the opportunity to teach classes at both Kent State and San Francisco State. In these classes and in community/school inservices, Beth had the forum to challenge teachers, future teachers, and child care providers to question their developing philosophies and to present positive information on community and school inclusion. Beth continues to try to make a difference through her work in TASH. "If elected to serve on the TASH Executive Board, it is my promise to continue that effort."

DONALD N. CARDINAL

Don Cardinal is relentless in his pursuit of equity and social justice for people with disabilities. He has worked for people with multiple and significant disabilities for over twenty years to create change—over a decade as a teacher, later as a director of grant projects to develop school-to-work transition programs, and he is currently Associate Professor, Director of Special Education, and Director of the Center for Educational and Social Equity at Chapman University in Orange, California.

Don has embraced the notion of school and community inclusion since 1974 when he worked for six years to move students from locked-facilities into public schools and community living. During this time, Don developed and implemented over 400 individualized community-based action plans for the purpose of moving students to least restrictive environments in school, community, work and living.

Don has published numerous writings on evaluation and the measurement of quality in special education and its techniques. His current research revolves around the assumption of competence of all people, paradigm shifts in research, and authorship in facilitated communication. His work has been cited in over 100 professional and media sources across nearly a dozen countries. When asked why he was interested in serving on the TASH Executive Board, Don responded "My life goal is to affect a meaningful change in the way society views disability. Toward that goal, there is no trade-off, no compromise, and no lethargy permitted. TASH has also demonstrated an unceasing commitment toward equity and social justice for people with disabilities. It would be an honor to work with TASH on our shared agenda."

Don has been a member of CAL-TASH since its beginning and is a frequent presenter at its annual conference.

PAM HUNT

Pam Hunt is an associate professor in the Department of Special Education at San Francisco State University. She served as the research coordinator for the California Research Institute on the Integration of Students with Severe Disabilities and has directed several federally-funded research projects. She has an active research history, and has published widely in the areas of communication, inclusive educational programs and practices, and social supports implemented in inclusive settings.

Pam has served as an advocate for students with disabilities and their families since her teaching days, often working closely with lawyers from Disability Rights Education and Defense Fund (DREDF). In her role as consultant to DREDF, she co-authored the original draft of the regulations for California's Hughes Positive Behavioral Intervention Legislation. Pam attempts to maintain a balance in her professional life between three passions: university teaching, research, and advocacy.

Pam is an active member of CAL-TASH.

JAY KLEIN

Since his involvement with the Youth ARC as a teenager, Jay Klein has made it a priority in his life to advocate for the inclusion of all people into our neighborhoods and communities. An author and educator, Jay has worked on issues related to supported living, housing, supported employment, inclusive education, policy and systems change, family leadership and coalition building.

Maintaining a strong commitment to families and working with Partners groups in several states, Jay's ongoing work as an educator affords a critical chance to change the way that professionals think and act toward people with disabilities. Jay has served seven years as a board member for a family-oriented newspaper in his community, as well as providing extensive consultation with numerous presentations and workshops nationwide.

Jay's strongest leadership role has been in the supported living movement, from providing traditional continuum-based services, to supporting people to live in and control their own homes and supports. In his work at the Institute on Disability, a University Affiliated Program at the University of New Hamshire, Jay received a grant for a three year demonstration project that successfully assisted twenty people with disabilities to own their own homes.

In 1994, Jay became the Director of the National Home of Your Own Alliance, a technical assistance center at the Institute on Disability. The mission of the Alliance is to advance the opportunities for people to own and control their homes by providing technical assistance to twenty-three state coalitions consisting of members of the housing and finance industry, service providers, and individuals. Jay has made a conscious effort to recruit, train, and support people with disabilities as paid staff, consultants, and advisory board members for the Alliance.

A TASH member since 1982, Jay has been a participant on the annual conference planning committee, chaired the

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Committee on Community Living, organized various TASH events, authored several articles for the TASH *Newsletter*, and has been a presenter at numerous state and national TASH conferences. In addition, he served as a board member for Colorado TASH from 1987-1990.

Jay's visions for the future of TASH are that it will strive to be more inclusive of people with disabilities and that it will seek to become more culturally diverse. Jay believes that TASH should maintain its leadership role on cutting-edge issues, policies, and practices on a national level.

TIM KNOSTER

"I am honored to be nominated to serve on the TASH Board. I hold a very special place in my heart for the TASH community and all that TASH represents. Collectively, we in the TASH community need to continue to provide leadership in order to further establish a greater array of inclusive communities and schools for all people, inclusive of people with disabilities."

Over the past decade, Tim has had a broad base of experiences. Tim's initial exposure and involvement with TASH was through grassroots efforts and networking that grew out of a number of social justice issues concerning people with disabilities. As a result, Tim helped to establish Pennsylvania TASH in the late 1980's and served as its first president. In his current role within the Instructional Support System of Pennsylvania (ISSP), Tim provides leadership to support the expansion of inclusive opportunities for children and their families. Tim has also served as an initiator to various forms of systems change activities related to interagency collaboration under the court order known as Cordero v. Commonwealth.

In Tim's work within the ISSP, he has guided policy review and development, as well as orchestrated training and technical assistance activities with interagency teams across the Commonwealth. He has been a lead proponent of positive behavior support and community organizing for children with histories of challenging behavior. Additionally, Tim has facilitated the infusion of inclusive practices into local school systems and communities, enabling a number of children who previously were relegated to isolated and segregated settings to access meaningful supports within their home schools and local communities. The focal point of all of these interrelated efforts has been in supporting families in partnership with service-providing systems to realize a personalized approach to framing supports around children.

Throughout Tim's adult life, he has focused his time and energy on working with families, schools, provider systems, and other important community members to provide support to children who are at great risk of being excluded and forced to live on the margins of society. "With this focus in mind, it would be a great honor and privilege to serve on the TASH board."

DEB KUNZ

"I am very honored to be nominated for a term on the Board of Directors of TASH. I am a parent advocate who has a commitment to creating a society which embraces diversity and includes ALL people. The most valuable learning experiences I have come from actively participating in my son's IEP meetings, as well as the many IEP/IFSP meetings I have attended supporting other families as they seek inclusive educational programs for their children." Deb is the Executive Director of Family T.I.E.S. Network, a not-for-profit parent and individuals with disabilities driven organization which provides education and advocacy services to families across the state of Illinois. Deb is a past member of the IL-TASH board.

Deb's passion for preserving and strengthening the role of families and students with disabilities in the educational process caused her to seek support from TASH for her position on the reauthorization of the Individuals with Disabilities Education Act (IDEA) in the 104th Congress. Working integrally with Marcie Roth, Governmental Affairs Director of TASH, Deb has been a leader in bringing together a national coalition of families and advocates in an attempt to prevent the erosion of procedural safeguards and the destruction of the civil rights of children. That effort continued in the 105th Congress as Deb assisted in bringing the voice of the grassroots to Washington in the weekly meetings held by the bi-partisan, bi-cameral working group established for IDEA Reauthorization.

Deb is also on the People First of Illinois' state team in the "Close the Door Campaign for Freedom." The campaign's goal is to close the state-operated facilities for people who have developmental disabilities. The campaign's position statement on closing institutions is as follows:

"We believe that all institutions, both private and public should be closed. All people regardless of the severity of their disabilities should live in the community with the support they need."

Deb would like to see TASH become the "Social Justice Clearinghouse" from which people across the country could access information to expand their efforts as they work to promote social equality and justice. Deb believes that TASH should continue to build on its efforts to ensure the right of people with disabilities to communicate using facilitated communication. "My son, along with many others who use FC, have been denied the right to communicate in schools and communities across the country. It is crucial that TASH continue to speak for those who have been silenced."

DIANNA WILLIAMS

Dianna has been involved with TASH leaders and members for over 15 years, which has changed her expectations and certainly the life of her son, Jay. Jay, now 27, is moving into his own home with Medicaid waiver supports. This is a reality Dianna had always dreamed possible. "With the support and encouragement of the TASH philosophy and values, Jay will have an opportunity we want for all persons with severe disabilities. Employment will be the next great equalizer for Jay as it is for all citizens."

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Being an active parent moved Dianna from the role of advocate to activist for her son as well as others. The natural progression was to develop an employment service for persons with disabilities, Assist, Inc., located in Terre Haute, Indiana. "To say that our work is over would be a delight, however, the constant vigilance to keep the movement forging ahead will always be a challenge to us all, particularly in the areas of self-advocacy, school, employment, and home ownership for persons with severe disabilities.

It is an honor to once again be nominated to the TASH board and, if elected, the values and philosophy shared by self-advocates, parents, and family members will continue to be the driving force for individuals with disabilities."

Dianna's current position as Co-President of the Indiana TASH board has given her a perspective that there is still much to be accomplished. Being on the national TASH board will offer an opportunity to further the person-centered community-based commitment parents and advocates share for persons with severe disabilities.

DONNA GILLES WILLIAMS

Donna has been actively involved with teaching individuals with disabilities, supporting their families, and training teachers and service providers for over 20 years. She has been a TASH member since 1978, is currently the President of the Florida Chapter of TASH, and had served as FL-TASH's representative on what was once known as the Delegates Advisory Panel for several years. Donna believes that a serious dialogue between TASH International and the chapters must be reopened in order to regain the sense of belonging that has been missing over the last several years.

Donna is a faculty member at the University of Florida, where she directs the Florida Outreach Project for Individuals with Deaf-Blindness and serves as Program Associate for the UF Center for Autism and Related Disabilities in Gainesville. Both projects provide technical assistance and training for families, school personnel, and other service providers who live with or work for people who experience a variety of significant disabilities. She has taught university courses at the University of Florida, the University of Maryland, and the Johns Hopkins University, and recently directed a federally-funded Model Inservice Training project in Florida.

Donna feels that it is critical that people with severe disabilities who are traditionally dismissed as incapable of having a voice are given control over decisions which affect the current and future quality of their lives. Because of this, her penchant is the development of respectful teaching and support practices for people with the most severe disabilities. She feels that the decline of segregated work and living options depends greatly on the job we do in the schools which, in turn, is dependent on the collaborative relationships we create among people with disabilities, their families, and the people who serve them.

JOE WYKOWSKI

"It is an honor to be nominated for the TASH board. My vision for providing support to people has been strongly influenced by an experience with what some people call disability, and that I consider a gift. The insight that I gained, after developing a rare disease that confined me to a wheelchair and then leg braces for a period of three years during my early childhood, provided me with an immeasurable education of the discrimination people encounter daily."

Joe's childhood experience afforded him a ticket to the world of special education. He was excluded from school for a year, then offered the opportunity to ride the special bus to school and excluded from activities because of his physical disability. Joe talks about this time in his life because it is to this period that he turns when reflecting on any person's dreams and desires for their life in terms of school, home, work and the type of support they should receive.

Joe is the Director of Community Vision, Inc., an individual support agency he founded in 1989 in Portland, Oregon. Community Vision is based on the concept of providing individualized supported living and employment supports, one person at a time.

In addition to his work at Community Vision, Joe consults and speaks nationwide on supported living, supported employment, community building and organizational change and development. As a consultant for the National Home of Your Own Alliance, currently assisting eighteen states to develop home ownership opportunities for people, Joe frequently draws from his own personal experience to help him understand how to promote home ownership and advocate for the right of all individuals to own and control their own home.

It has been 14 years since Joe became a member of TASH. Joe has actively supported TASH board members, attended TASH board meetings, and served as a member of the conference committee, assisting with conference presentation submission reviews on numerous occasions.

Under TASH's current structure, Joe is the co-coordinator of the Open Project Group on Community Living and Employment. He has been a member of the Community Living Interest and Action Group since its inception and as a member and co-coordinator of the Community Living Committee, Joe has assisted with coordinating the Community Living Gathering TASH Tech and Strand for the annual conference for the past five-years. He believes the Community Living Committee has played an integral role in shaping the structure of TASH. Its main goal has been to develop participation for all people throughout the alliance.

"If elected, I will continue the work of assuring TASH's role as a full participation organization by creating more opportunities for individuals, regardless of support needs, to attend the conference and to serve on committees throughout the year. I believe that TASH's most prominent strength is the diversity of its members. As a board member, I will continue to work hard to effectively represent TASH's collective voice for all people."

TASH 1997 Election of Five (5)

EXECUTIVE BOARD MEMBERS

Term of Office: 1997-2000

— OFFICIAL BALLOT —

There are five positions for members of the TASH Executive Board to be filled this year. Positions will be filled via ballot by dues-paying TASH members (one each) in accordance with the Association's By-Laws. The Executive Board member-elects will begin their terms at the Annual Board Meeting held in conjunction with the 1997 TASH Conference, December 10-13 in Boston, Massachusetts.

Ballot Instructions:

You should vote for a total of FIVE nominees. Ballots containing more than five votes are invalid. Please mark your ballot in ink.

☐ **Michael Auberger**
☐ **Beth Brennan**
☐ **Don Cardinal**
☐ **Pam Hunt**
☐ **Jay Klein**
☐ **Tim Knoster**
☐ **Deb Kunz**
☐ **Dianna Williams**
☐ **Donna Williams**
☐ **Joe Wykowski**

For information about the candidates, please refer to pages 21-24 of this issue of the TASH *Newsletter*.

Mailing Instructions:

Ballots can be returned using this postage-free mailer, or originals of the ballot can be sent in an envelope. If you elect to use an envelope, please be sure the word BALLOT is printed on the front. If you use an envelope, please do not place anything other than your ballot inside; your envelope will not be opened until the counting of the ballots.

VERY IMPORTANT:

ONLY AN ORIGINAL BALLOT WILL BE CONSIDERED VALID.
PHOTO COPIES OR FAXES WILL NOT BE ACCEPTED.

Ballots must be received at the TASH Central Office by
SEPTEMBER 30, 1997

Mail your completed ballot to:

TASH, 29 W. Susquehanna Avenue, Suite 210
Baltimore, Maryland 21204
Attn: Ballot

☑ 1997 TASH Executive Board Election BALLOT Due in Baltimore on September 30, 1997!

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Supported Employment: TEN YEARS AFTER

BY MICHAEL WEST, PH.D, PAUL WEHMAN, PH.D, GRANT REVELL, MS, MED, AND JOHN KREGEL, ED.D

For over a decade, supported employment has been a service option for individuals with severe disabilities served by the Vocational Rehabilitation (VR) system. In that time, the program has experienced unparalleled growth, from fewer than 10,000 participants at the program's inception in 1986, to over 135,000 in 1995. During this same period, the Rehabilitation Services Administration (RSA) has also expended money to the states for systems change to promote community-based employment for individuals with significant disabilities.

Supported employment combines job placement assistance and training (time-limited services) funded by the VR agency, with ongoing support (extended services) for job maintenance. The initial supported employment regulations defined the target population as individuals with significant disabilities for whom competitive employment has not traditionally been an option, and for whom ongoing supports (i.e., extended services) are essential to maintaining competitive employment. Amendments to the Rehabilitation Act in 1992 redefined the target population as those "with the most significant disabilities," in an effort to insure that programs serve those who are truly in need of intensive and ongoing supports.

As part of its federally-funded research efforts in supported employment, the Rehabilitation Research and Training Center on Supported Employment at Virginia Commonwealth University (VCU-RRTC) undertook a National Provider Survey, targeting agencies "vendored" by state VR systems to provide supported employment. Vendor lists were obtained from 40 state VR agencies and 385 vendors were sampled for the survey. Extensive telephone surveys, covering a number of service delivery issues, were conducted over the course of approximately eight months by eight telephone interviewers. The following sections will describe some key findings from the survey.

Services to Individuals with the Most Significant Disabilities

Several previous studies have suggested that the program's target population, individuals with "the most significant disabilities," are underserved. To address this question, respondents were requested to estimate the percentage of their consumers who typically received more than two extended service contacts per month, the minimal level of extended services under the current regulations. An average of 41% of the individuals in extended services received more than two contacts per month, with 6 of 10 receiving only minimal levels of support. Estimates ranged from 0% (no consumer received more than minimal levels of service), to 100% (all did).

It is evident from these findings that supported employment providers show remarkably diverse degrees of endorsement for the program's mission of serving those with the most extensive and challenging support needs.

Use of Social Security Work Incentives

The survey found that over half of supported employment agencies utilized the PASS (Plan for Achieving Self-Sufficiency) and IRWE (Impairment Related Work Expenses) programs for the individuals they support. Within the previous year, they had written PASSes and documented IRWEs for 13.3% and 10.2% of their caseloads, respectively. While these percentages may seem small, they exceed the proportionate use of work incentives among working SSA claimants as a group, and only represent PASSes and IRWEs written over the previous year. Thus, PASSes and IRWEs appear to be used to a significant degree by supported employment agencies and individuals. Moreover, the survey also found that individuals are involved to a great extent in choosing PASS/IRWE objectives and completing the necessary documentation. PASSes and IRWEs were most often used for purchasing transportation services, but were used to purchase a number of employment-related tools, equipment, and services, including supported employment services.

Over one-third of the respondents (38%) stated that they had experienced no problems in accessing PASSes and IRWEs. However, 62% of responding agencies reported at least one problem in accessing these work incentives for the individuals they support. Most of the reported problems tended to involve administrative processes within SSA for submission and approval, such as a lengthy approval process and inconsistency of approvals.

Conversion from Segregated to Supported Employment

Approximately 37% of agencies with both facility-based programs and supported employment, indicated that

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SUPPORTED EMPLOYMENT: TEN YEARS AFTER

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they had converted resources from segregated services to community-based employment. After an average of five years of conversion, over half of the agencies' budgets and the individuals supported by the agencies continued in facility-based programs. Boards of Directors, funding agencies, and individuals were perceived to be very supportive of conversion, but reluctance of family members and agency staff was perceived to be a significant barrier to conversion.

Federally-funded systems change projects have resulted in a substantial number of rehabilitation facilities converting staff and other resources to some degree in order to increase supported employment opportunities. Still, the degree of change is not that which was hoped for in the 1980s. Segregated vocational services continue to be the predominant mode of service for individuals in need of extended employment support. In most communities, existing facilities are the only avenue of access to supported employment and, for the most part, they remain committed to segregated services.

One possible strategy to address this problem is to redirect systems change and demonstration grants to spur the development of new, stand-alone supported employment vendors. These vendors, unlike existing rehabilitation facilities, would be unencumbered by histories of segregated service and values. Grant funds can be targeted to provide access to supported employment in areas where facility-based programs have failed to do so to any substantive degree.

Use of Natural Supports

The survey found that the natural supports concept has been embraced by the field of supported employment, with over 85% of the agencies surveyed indicating that they emphasize natural supports in service delivery. Those agencies that emphasize natural supports reported that they typically used coworkers or supervisors for initial training, and for ongoing monitoring of work performance. Natural supports were used far less frequently in job development and placement.

Vendors of supported employment services have a responsibility to positively assist job change decisions and other career development choices made by individuals.

Programs were also far less likely to use employer resources (i.e. employee assistance programs), family members or friends, resources of the individual receiving support, or community involvement (e.g. civic groups, professional organizations, churches, etc.) as natural supports. Thus, while most agencies report that they emphasize natural supports, the types of supports and their functions are somewhat limited.

Most programs feel that the use of natural supports had contributed to the overall success of their supported employment programs. However, about two-thirds of the respondents indicated that they had experienced problems in the implementation of natural support strategies. These problems overwhelmingly fell into two areas.

First, employers were unwilling to implement the natural support strategies recommended by the supported employment program, and were resisting assumption of sole responsibility for the training, supervision and support of the employee with a disability. Second, providers were having a difficult time identifying staff members with the skills necessary to implement natural support strategies, or to provide training to current staff members in the use of natural support techniques.

Some writers have expressed concern about the growing emphasis on natural supports, and the potential impact on service access for those with very significant disabilities. Eight of ten respondents indicated that they had found natural supports to be useful and relevant for all members of their caseload, including those who are the most difficult to place, train, and maintain in employment. Among those reporting to the contrary, the primary reason was based not on the types of individuals served, but by characteristics of the employment settings into which individuals were being placed. Among the reported instances where natural supports did not "work" were such factors as fast-paced or high stress jobs or environments, highly competitive businesses, and workplaces that weren't particularly friendly to any worker, disabled or not.

Funding Methods and Impact on Service Quality

Survey respondents were requested to identify the type of time-limited and extended funding mechanisms through which they were reimbursed for providing services. Time-limited services were predominantly funded through fee-for-service agreements using either a negotiated hourly rate, or a state-wide fixed hourly rate (47.7%), followed by slot-based agreements using a daily or more extended time frame (27.2%), outcome- or performance-based agreements (14.3%), and other funding agreements (10.8%). Extended services were predominantly funded through slot-based agreements (44.3%), followed by hourly fee-for-service agreements (27.3%) and other funding methods (28.4%).

Respondents were also requested to indicate if the methods of funding for services had an impact on service delivery in several key areas. With regard to time-limited services funding, statewide fixed hourly rates were found to discourage both conversion to community integrated employment opportunities, and the reopening of supported employment cases after job loss at a level significantly higher than the other funding methods. Negotiated rates for specified outcomes were viewed most favorably in these same areas. Within each of the three funding categories, the

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SUPPORTED EMPLOYMENT: TEN YEARS AFTER

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statewide fixed rate options were viewed as more negative in terms of conversion and reopening cases, as compared to negotiated rates. In addition, funding methods utilizing negotiated rates were seen by providers to adequately cover costs at a level significantly higher than state-fixed rate methods.

Similar perceptions were found for extended services funding. Respondents who were reimbursed using statewide fixed hourly rates indicated that their funding method was less responsive to individual choice, and discouraged movement of individuals and resources from segregated to community based programs.

With regard to individual choice, the Rehabilitation Act Amendments of 1992 emphasize the importance of individual choice in the establishment of job and career goals and the selection of services. Vendors of supported employment have a responsibility to respond positively to choices made by the individuals they serve, and particularly those regarding job changes, an essential component of career development. However, the use of fixed hourly rates may present financial disincentives for providers in assisting individuals to make voluntary job changes for the purpose of career advancement, or simply locating a better job match.

With regard to movement from segregated programs to supported employment, the Rehabilitation Act unambiguously endorses competitive employment as the option of choice for all individuals, regardless of the extent of their disabilities. Yet, all available evidence indicates that supported employment staff and individuals remain small in comparison to segregated, facility-based services. The staff and funds currently committed to supporting center-based services represent a substantial potential resource for expanding supported employment opportunities. Funding methods are needed that encourage and support service providers to expand community based service capacity.

For example, flexible rate systems can be designed to cover excess costs to providers for serving individuals with more intensive support needs or employment barriers, or provide incentives for assisting individuals to achieve more positive outcomes in terms of job choice, wages, benefits and integration.

Another crucial policy issue is access to services for those with the most significant disabilities with presumably more complex support needs. The findings of this investigation indicate that vendors who are able to negotiate rates have more financial incentive to include members of this group in their service populations. Thus, flexible reimbursement schedules, based on individual characteristics, can be a positive strategy for achieving this critical mission of the program.

The potential impact of these findings on state and national policies is clear and unambiguous. For supported employment to supplant segregation as the option of choice for persons with extensive support needs, agencies which provide these services must be reimbursed using methods that encourage service expansion, and which adequately account for service costs. When providers are able to negotiate with funding agencies, such variables as individuals' support needs, quality of anticipated outcomes, and community characteristics, can be more readily taken into account.

Supported employment service providers and individuals utilizing those services have a common interest to advocate for service funding methods that promote quality services and outcomes. Service capacity of these programs needs expansion to accommodate anyone who wants and needs ongoing support to achieve competitive employment.

Supported employment policies and service delivery methods continue to evolve in light of ongoing research in best practices. The VCU-RRTC National Provider Survey found both encouraging advancements in the field, as well as continuing challenges to the program's mission. Of particular interest are the positive perceptions of vendors who use either negotiated rate funding methods or outcome-based funding. Providers and individuals utilizing supported employment services and have a common interest to advocate for service funding methods that promote quality services and outcomes. Service capacity of these programs needs expansion to accommodate anyone who wants and needs ongoing support to achieve competitive employment.

There should be no doubt that RSA systems change funding has had a significant impact on the growth of state investment in supported employment, and that thousands of individuals with significant disabilities have benefited. However, without alternatives to facility-based programs and efforts to address the concerns of families, the mandates of the Rehabilitation Act — for choice, self-determination, and competitive employment as the option of choice — will remain unfulfilled promises for the majority of individuals with significant disabilities.

The authors can be contacted c/o: Rehabilitation Research and Training Center on Supported Employment, Virginia Commonwealth University, Richmond, VA 23284-2011.

Additional findings from the VCU-RRTC's National Provider Study will soon be available at the center's World Wide Web site: http://www.vcu.edu/rrtcweb/

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to represent the United States at the 1996 World Special Olympics. I especially didn't need TASH's blessing to be proud of him. But it sure would have been nicer had TASH had the guts to say something positive about Special Olympics before 1997.

My story doesn't end with Special Olympics because it is only part of the journey. Jonathan is the only member of the Class of 1998 of Swampscott (Massachusetts) High with a cognitive disability. Last year, he had a 7-2 record on the junior varsity golf team. His dream is to make the 1999 World Team and represent the United States at the Special Olympics. All this without Tiger Woods for motivation!

Why is it only okay for people with disabilities to have choices if they choose what someone else wants for them? All over the world there are over a million athletes participating in Special Olympics. I have never seen anyone forced to participate, so why do so many of you think they have made a bad choice?

My son participates in Special Olympics and in regular competition and by doing so, he has followed a family tradition of sorts. As a competitive swimmer 30 years ago, I participated in regular AAU competition in the "segregated" Maccabiah events where only Jews are allowed to participate. I never heard anyone say that we shouldn't have the opportunity for those experiences. Today, there are "gay" games and to say anything negative about either of these events would be inviting accusations of anti-Semitism or homophobia. By this standard, those of you without disabilities who condemn Special Olympics need to ask yourselves if you have the right to do so.

— Jo Ann Simons
Wakefield, MA

I'm against Special Olympics for the same reasons I'm against special education, sheltered workshops, group homes, schools for women, schools for African-Americans, schools for students who are gay, organized religion, organized sports and anything else that puts people into boxes based on a certain set of charactertistics. I realize that there are pervasive social injustices that create all these separate entities and are created by them. Unless we get to the root cause, they will always exist.

I am not an idealogue, but an idealist who believes that there is a way for all of us with all our myriad differences to co-exist peacfully - and full inclusion is the road that will take us there. This idealism has led me to be uncomfortable in any environment where everyone has the same label (whether it is disabled, white, black, poor, Buddhist, senior citizen, etc.).

I have participated in Special Olympics, just as I have taught in segregated schools, played segregated sports, and belonged to a segregated religion. I changed in order to belong to a larger, diverse community.

I'm not advocating taking away anyone's needs or desires. I'm asking that we keep trying to create a world that won't force people into "separateness." For me, this is nothing less than working toward world peace. (See comments of Tom Sinclair on page 5 of May 1997 *Newsletter*).

Maybe the following quote speaks more directly to where TASH, as well as our culture, is headed: "The world will not be saved by old minds with new programs. If the world is saved, it will be saved by new minds with no programs . . . Vision is the river and we who have been changed are the flood." - Daniel Quinn

— Alan Berger, New York

I read David Hingsburger's article on Special Olympics with much interest. While I found the article both intriguing and annoying, Hingsburger hits on a key issue when he recognizes and appreciates how athletic endeavor, even when confined to limited opportunities such as Special Olympics, can yield real benefits. At the same time, he doesn't do the essential work of bridge-building that TASH should be about as it works on inclusion. Hingsburger could have reached out to the membership to discuss ways of connecting interest in athletics, real world struggles with finding opportunities for sports participation, etc.

Why didn't he recognize the possibility that many of us who are critical of Special Olympics also recognize the reality that many people with disabilities like the athletic opportunities it provides? And, clearly, this position is not antithetical to our push for inclusion. Some people in institutions have had opportunities to learn how to read, and we would never deny those opportunities, even as we work to make inclusion the standard.

Separate, disabled-only sports — like Special Olympics — may have a place alongside inclusive opportunities. But segregation is never adequate if it's all people have.

— Douglas Biklen
Syracuse, NY

TASH welcomes Letters to the Editor. If you would like to submit an opinion on an issue you've seen addressed in the *Newsletter*, send your correspondence to: Priscilla Newton, TASH *Newsletter*, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204. You can also fax or e-mail your letter: (410) 828-6706; <pnewton@tash.org> Letters (or excerpts) may be reprinted in upcoming issues of the *Newsletter* as space allows.

NICHCY

The National Information Center for Children and Youth with Disabilities

Access NICHCY!
for a world of information on disabilities

Call:
1-800-695-0285 (V/TTY)

E-mail:
nichcy@aed.org

Gopher:
gopher aed.org

Web:
http://www.nichcy.org

Write:
P.O. Box 1492
Washington, DC 20013

Fax:
202-884-8441

EXECUTIVE DIRECTOR POSITION

COMMUNITY SYSTEMS, INC. (CSI) of Torrington, Connecticut is recruiting for a new EXECUTIVE DIRECTOR.

CSI is a nine-year old company which provides residential and vocational opportunities to persons with developmental disabilities. Most often the persons we serve also have additional challenges which may include mental illness, significant medical conditions and sensory impairments. Our 250-person staff assist 70 people in small group settings, individual apartments, vocational enclaves, and 3 ICF/MRs.

CSI seeks a seasoned professional, at least Master's prepared, or an RN, with a minimum of ten years of experience, five of which must be in the direct provision of services to people. Our Executive Director is the clinical leader, but operates in a "bottoms-up" environment where the line staff are recognized as the keys to achieving our mission:

"Helping people with disabilities to find happiness in their homes, lives and communities."

CSI provides its services in the Northwest corner of Connecticut in beautiful Litchfield County. We offer a competitive compensation package and a willing, dedicated staff. Please send resume/vitae and letter of interest to:

Executive Search
Community Systems, Inc.
295 Alvord Park Road
Torrington, CT 06790

CSI actively supports workplace diversity. EOE/AA/M/F/D/V

Looking For Information?

The National Resource Center is designed to promote the full inclusion of people with developmental disabilities in community life. Funded by the National Institute on Disability and Rehabilitation Research (U.S. Department of Education), the National Resource Center continues the Center on Human Policy's work in the area of training, technical assistance, consultation and information dissemination.

Through the National Resource Center, the Center on Human Policy has a toll-free number available for individuals or organizations looking for information. Please give us a call and share this number with anyone who may be interested.

THE NATIONAL RESOURCE CENTER
1-800-894-0826
We can also be contacted at:
CENTER ON HUMAN POLICY
Syracuse University, School of Education
805 South Crouse Avenue
Syracuse, New York 13244-2280
(315) 443-3851 (voice)
(315) 443-4355 (TTY)
(315) 443-4338 (fax)
e-mail: thechp@sued.syr.edu
WWW: http://web.syr.edu/~thechp

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on language "that emphasizes the humanity of people with handicaps." Terms such as "the autistic," "the retarded," and "the severely handicapped" refer to characteristics, not individuals. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Executive Board

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Referred by:

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Telephone: ( ) ______________ Fax: ( ) ______________

Please Check Appropriate Categories
(not more than three):

( ) Administrator
( ) Adult Service Provider
( ) Case Manager
( ) Day Personnel
( ) Early Childhood Services
( ) Educator (University/College)
( ) Early Intervention Specialist
( ) Friend
( ) Gov. Personnel (Federal, State, Local)
( ) Higher Education
( ) Human Services Provider
( ) Interested Individual/Advocate
( ) Legal Administrator
( ) Occupational/Physical Therapist
( ) Paraprofessional/Direct Care
( ) Parent/Family Member
( ) Primary Care Provider
( ) Personal Assistant
( ) Professional Advocate
( ) Psychologist
( ) Regular Education
( ) Residential Services
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Student (College/University)
( ) Support or Related Services
( ) Supported Employment Personnel
( ) Teacher (Direct Service)
( ) Teacher Trainer
( ) Vocational Services
( ) Other

General Membership (individual)	$85.
Agency/business/university/ college/library/school (allows three conference attendees)	$190
Self Advocate, Parent, Full Time Student, Direct Careworker/Paraprofessional/ Personal Attendant (for whom payment of full fee would present a hardship)	$45
Family (group rate)	$130
Lifetime Member	$1000

All dues are $15 higher for members outside the U.S. & Canada. Funds must be submitted in U.S. Dollars.

If you would like to charge your membership, please fill in the necessary information:
( ) Mastercard ( ) Visa ( ) Discover

Card Number ______________________________

Expiration Date ______________________________

Signature ______________________________

( ) I would like to arrange to spread my payments out.
Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

How did you learn of TASH ______________________________

What, in particular, inspired you to join ______________________________

What other disability organization do you belong to ______________________________

If you are applying for a student membership, please provide the following information:

Department ______________________________

College/University ______________________________

Student I.D. Number ______________________________

Anticipated year of completion ______________________________

( ) Please check here if you would like us to send information about your local TASH Chapter.

Please make check payable to: TASH
Address: 29 W. Susquehanna Avenue
Suite 210
Baltimore, MD 21204
Telephone: 410/828-8274 Fax: 410/828-6706

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Address Correction Requested

IMPORTANT!
Dated Material INSIDE!
TASH Board Election Ballot

JUNE/JULY 1997

Newsletter

WE THE PEOPLE
ALL THE PEOPLE!
EQUALITY
DISABILITY RIGHTS!
INCLUSION
NOW!

TASH CONFERENCE

Preliminary 1997 TASH Conference Agenda

SHERATON BOSTON • DECEMBER 10-13

BEST COPY AVAILABLE

Skill Development Products for Paraeducators, Teachers, and Parents

ParaEducators: LifeLines in the Classroom

Five Training Modules for Instructional Paraprofessionals Supporting Students with Disabilities in General and Special Education Classrooms

LifeLines

- Module 1 - Defining the Role of the ParaEducator
- Module 2 - Celebrating Similarities: Students with Disabilities
- Module 3 - The IEP Process: The Role of the ParaEducator
- Module 4 - Supporting the Instructional Process
- Module 5 - Behavior Improvement Strategies

Melding

A Partner Teacher's Guide to Working with ParaEducators who Support Students with Special Needs

Processes and Tools to:
- facilitate negotiation of roles and responsibilities
- foster initial and on-going communication
- promote collaborative problem solving

That result in:
- a positive working relationship between partner teacher and instructional paraprofessional
- best possible services and supports for students with special needs

Students FIRST: Parents as Partners in the Special Education Process

A Training Module for Proactively Building Knowledge, Understanding and Trust to Develop a Strong Family-School Partnership

- Special Education Terminology and Process
- IEP Data Collection and Reporting
- Continuum of Special Education Services
- Transition and Future Planning
- Procedural Safeguards
- Communication Strategies

Students FIRST

For more information on training topics, consultative services or other products, please contact...

LRConsulting • P.O. Box 6049-747
Katy, TX 77491-6049
(281) 395-4978 • Fax: (713) 973-1271 • http//www.lrconsulting.com

Look for over 400 incredible sessions & special events at the TASH Conference including:

- *Pre-Conference Full Day Workshops*
- *Exhibits, Media Festival, and Job Exchange*
- *Childcare/Youth Activities*
- *Information you will not find anywhere else on these topics and much more!*

The TASH Conference promises to deliver the very latest in resources, information, and contacts that are available to assist individuals with disabilities live full and inclusive lives. Many leaders in the disability field who have exhilarated and renewed you in the past will be back, and every year new people come to share lessons learned from personal and professional experience. Look for sessions on topics like:

Community Living and Employment

- *Aging Issues*
- *Advocacy Techniques and Strategies*
- *Assistive Technology Information and Tools*
- *Community Living/Community Building/Housing*
- *Death and Dying Issues*
- *Employment of People with Significant Disabilities*
- *Facilitated Communication*
- *Family and Multicultural Issues*
- *Leisure and Recreation*
- *Life Transitions & Changes in Support*
- *Managed Care Funding Issues*
- *Research Strategies,Outcomes, & Implications*
- *Sexual Expression, Romance, Dating*

Early Childhood and Inclusive Education

- *Advocacy Techniques and Strategies*
- *Assistive Technology Information and Tools*
- *Challenges of Providing Services to People with Complex and Significant Disabilities in Community Schools and During Transition*
- *Collaborative Teamwork & Paraeducator Issues*
- *Dealing Productively with Children Who Significantly Challenge Schools But Don't Have Labels of Significant Disabilities*
- *Effective Strategies for Communication*
- *Implications for Implementation of IDEA*
- *Higher Education Restructuring*
- *Instructional Strategies & Curriculum Design*
- *After School Leisure and Recreation*
- *Multicultural Family & Curriculum Issues*
- *Paths, Maps, and Building Circles of Friends*
- *Personnel Preparation*
- *Research Strategies,Outcomes, & Implications*
- *Related Services & Special Health Care*
- *Successful Systems Change & School Reform*
- *Urban Education Issues*

Issues on Rights, Ethics, Society

- *Advancing the Use of Positive Approaches to Deal with Challenging Behaviors*
- *Closing Institutions & Promoting Supports and Funding for Community Living*
- *Increasing the Impact of Grassroots Advocacy*
- *Empowering Individuals and Families*
- *Eliminating All Obstacles to Full Inclusion*

and more!

" In the squares of the
city, by the shadows of the
steeple,
Near the relief office
I saw my people
And some were stumbling
and some were wondering
if this land was made for
you and me."
Woodie Guthrie
"This Land is Made for
You and Me"

The 1997 TASH Conference is in Boston, a city with an impressive history inspiring action. A perfect match for an organization known for the same! "Inclusion" is not necessarily a revolutionary idea. However, the actual realization of true inclusion still has many miles to go, and there are still many battles to win. This is *the* opportunity to learn and share from the people whose combination of personal experience and professional expertise have led the disability movement. Over 2,400 advocates, educators, disability leaders, university personnel, community members, family members, and others who believe in the values you do attend the TASH Conference.

The TASH Conference has always had incredible motivating power! Specific sessions that give in-depth and practical information on vision, goals, strategies for implementation, and systemic evaluation of the full spectrum of inclusive living will be offered. This is one conference you can't afford to miss!

TASH dedicates the 1997 Conference to Gunnar Dybwad, who has been a life long advocate for the rights of people with disabilities. Gunnar, a long time friend of TASH, has enlightened millions of people around the world regarding the philosophy, methods of support, and strategies for education and empowerment of individuals with disabilities. Gunnar's delightful sense of humor, his exhaustive knowledge of the field, and the ability to both see deep into the issues and to act uncompromisingly, have guided his extraordinary work with parent groups, self-advocates, voluntary organizations, state departments, and federal governments around the world. Gunnar, along with his wife, Rosemary, have brought encouragement, hope, and new currents of thought to us all.

Check Us Out! http://www.tash.org

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TASH (The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

–

Building communities in which no one is segregated and everyone belongs

–

Forging new alliances that embrace diversity

–

Advocating for opportunities and rights

–

Eradicating injustices and inequities

–

Supporting research and disseminating knowledge and information

–

Promoting inclusive education

–

Supporting progressive legislation and litigation, and

–

Promoting excellence in services

FROM THE EXECUTIVE DIRECTOR

BY NANCY WEISS

As some of you know, I was a TASH member for many years before becoming a part of the TASH staff. I remember waiting for the Conference *Newsletter* with anticipation. It was the first chance to see who would be there, what sessions were planned in my areas of interest, and some years, to see my own name and session description in print. Receiving the Conference *Newsletter* was also a signal that summer was drawing to a close and that it was time to start working on my boss to assure that I'd be able to attend!

Well here it is! I can't remember a year when I wasn't excited upon receiving the Conference Newsletter. And this year's edition is more exciting than ever. We have almost 450 sessions planned with over 800 presenters - lots of first time TASH presenters who are doing exciting things across the country as well as loads of the best-loved favorite presenters of years past.

There are 91 sessions planned on adult issues and self-determination, over

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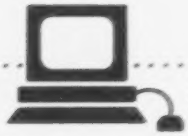
WHOM DO I CONTACT??



- **For questions about conference registration or exhibiting call:** Rose Holsey, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For issues of policy, chapter or committee support or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on the conference, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For information on government affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:mroth@tash.org
- **For information on membership, permission and reprints, newsletter advertising, or publication/video sales, call:** Priscilla Newton, Director of Member Services, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the newsletter or to make a submission, call:** Priscilla Newton at (410) 828-TASH, Ext. 102.
- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230, e-mail: lgoetz@sfsu.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail: pnewton@tash.org

From the Executive Director

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100 on inclusive education, 30 on employment, 37 on positive approaches to behavior change, and a number of additional sessions on early childhood, family issues, advocacy, higher education, international issues governmental affairs, recreation & leisure, multicultural issues, urban concerns, management issues, transition from school to work, sexuality and sexual expression, systems change and the list goes on and on.

Don't miss this year's big event. Both newcomers and seasoned attendees find the TASH conference to be welcoming, exciting, diverse, and inspiring. I can't remember ever leaving a TASH conference without feeling re-charged, energized, anxious to share what I had learned, and without having made a wealth of valuable contacts. TASH is the one conference I would attend at which the lines between family members, self-advocates and professionals are blurred. As a Board member said recently, it's the one place where research, best practices and self-determination are not viewed as contradictions. It was the conference at which I felt comfortable making real contact with all those wise people whose books lined my shelves and at which I always have felt at home. At the TASH conference, I wasn't some crazy ideologue paddling upstream, but a kindred spirit in a place overflowing with people who shared my beliefs and ideals.

Now that my role has changed, the spirit and optimism of TASH and TASH's annual conference still drive me and remind me what it's all about. I hope you will make your plans now to join us for this important event. And if you do — don't hesitate to come up and say, "hi!"

SHERATON BOSTON HOTEL & TOWERS

39 Dalton Street • Boston, Massachusetts 02199 • (617) 236-2000

DIRECTIONS:

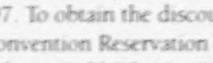
I-90/Massachusetts Turnpike, Exit 22, Prudential Center
T-Green Line, Prudential Center stop or ♿ Blue Line to Orange Line, Back Bay/South End stop.
The conference site is 5 miles from Logan International Airport, and will cost approx. $15.00 per trip. Massport Taxi service runs accessible and non-accessible transporation. Go to taxi stand and request service upon arrival. For questions call 1-800-23-LOGAN or 1-617-561-1769.

Check out the: Sheraton website: www.sheraton.com
Boston website: www.toboston.com

1997 Hotel Rates

$129.00 Single, $137.00 Double. Make your reservations early to assure space. Room block is held until November 10, 1997.

Official TASH Conference Airline



US Airways has been designated as the official carrier for attendees of the TASH Conference. US Airways agrees to offer an exclusive low fare. This special fare will offer a 5% discount off First Class and any published US Airways promotional round trip fare. A 10% discount off unrestricted coach fares will apply with 7 days advance reservations and ticketing required. These discounts are valid provided all rules and restriction are met and are applicable for travel from all points on US Airways route system.

The above discounts can not be combined with any other discounts or promotions, and are valid between December 5-17, 1997. To obtain the discounts, you or your travel agent must call US Airways Meeting and Convention Reservation Office at 800-334-8644; 8:00 am – 9:00 pm Eastern Time. Refer to Gold File No. 77680250

Last year over 50 people with disabilities and/or family members of people with disabilities were able to attend the conference because you stayed at the TASH headquarters hotel and/or used the official airline. Thank you! Let's continue that effort and make it possible for even more people to attend this year's conference in Boston. Make your reservations early — the holiday season is a busy time for an exciting place like Boston — don't delay, do it today!

THURSDAY, DECEMBER 11, 1997
3:30 - 5:45

Campaign for Freedom

Tia Nelis and Members of *Self Advocates Becoming Empowered* (SABE)

Join SABE as they share information about, and plans to implement their belief that all institutions, both private and public, should be closed. All people regardless of the level of disability should live in the community with the support they need. Join in the campaign!

◆

Tribute to Gunnar Dybwad

◆

Presentation of the 1997 TASH Positive Approaches and Media Awards

◆

David Hingsburger

Dave is a consultant, lecturer, and widely published author. He has extensive experience working with people with disabilities, and specializes in provision of education and consultation for staff and agencies and counseling for people with disabilities in the areas of problematic behaviors, and inappropriate or deviant sexual behavior. He has written extensively in magazines and journals, and co-authored several books including: *Changing Inappropriate Sexual Behavior*; a seventeen book series written for people with disabilities; and *Being Sexual: An Illustrated Series on Sexuality and Relationships*. David is the sole author of the acclaimed *"I Series,"* which, along with his latest books, *Just Say Know! and Behaviour Self!*, have been well received.

Shafik Asante

Shafik was born and raised in the city of Philadelphia. As the founder of New African Voices Alliance, Shafik brought together African American community organizers to fight against the many injustices prevalent in the African American community. As director of COMMUNITY AWARENESS NETWORK, Shafik worked with diverse cultures, uniting them in struggles for better community services. Shafik has won numerous awards for community organizing and as an outstanding community leader. Shafik has gained national and international recognition as both an article writer and presenter. He is an affiliate of the California-based Tools for Change and the Canadian-based Center for Integrated Education and Inclusion. Shafik advocates for people with "unrecognized abilities," as well as other diverse groups often excluded from society.

FRIDAY, DECEMBER 12, 1997
3:30 - 5:45

"The Sky is the Limit" Performance

Cynthia Archibald, Florri Aversa, William Henderson, and children from the Patrick O'Hearn School in Boston.

This performance features students from the Patrick O'Hearn School, a fully inclusive elementary school in Boston. This colorful and inspiring performance will include music, dance, and strong visual elements. Children of all ability levels will participate.

◆

Presentation of the 1997 TASH Collaboration and Alice H. Hayden Awards

◆

Celebration/Sing Along — Join Mara-Sapon Shevin and Mayer Shevin as they wrap up the Friday Plenary with a short and inspiring celebration that will be a prelude to the fun later in the evening! (next page)

◆

Joyce Buell

"There was a time when the continuum of options for children with disabilities included burning at the stake or let's keep him in the attic with the Christmas decorations." With these words, Joyce Buell began her acceptance speech for the 1994 Illinois TASH Parent Award and as her new role as guest speaker at disability-rights conferences across Illinois. Inspired and provoked by the challenges of parenting a child with a disability in today's society, Joyce has written a collection of powerful and touching poems. Together her poetry, prose, and photographs create a three-dimensional scrapbook that delights and enlightens audiences. Joyce is a University of Rochester graduate, a former teacher, and the parent of Maggie 13, and Don 17, who has Down Syndrome. Joyce's one woman show is entitled, "Fingerprints on My Heart."

Reed Martin

Reed is an attorney who has represented individuals with disabilities for over 25 years. With the publication of his book *Educating Handicapped Children: The Legal Mandate in 1978*, Reed has been recognized as a national voice in special education law. Among other cases, he represented the family in Irving I.S.D. v Tatro and the family in Daniel R. v. State Board of Education. Reed has produced videotapes, given lectures, and has written and edited publications of cases and materials on disability law topics. His most recent book is on *Extraordinary Children Who Want Ordinary Lives*. Reed is the parent of a child who received traumatic brain injury 15 years ago. With accommodations and service under Section 504 and IDEA, he completed school in regular education classes.

Tentative Conference Agenda

Tuesday, December 9, 1997
8:00 – 9:30 PM Pre-Conference Registration

Wednesday, December 10, 1997, Pre-Conference Activities
7:30 – 9:00 TASH Tech Registration
8:00 – 4:30 Club TASH Day Care/Youth Activities
9:00 – 4:00 TASH Tech Workshops
9:00 – 4:00 TASH Chapter Development & Leadership Training
2:00 – 8:00 TASH Conference Registration
5:00 – 7:00 Opening Reception in the Exhibit Hall

Thursday, December 11, 1997
7:30 – 3:00 TASH Conference Registration
7:45 – 5:30 Club TASH Day Care/Youth Activities
8:00 – 5:00 TASH Exhibit Hall Open
8:00 – 3:15 Conference Sessions and Poster Presentations

3:30 – 5:45 Plenary Session And Awards
5:00 – 6:30 No Host Reception

Friday, December 12, 1997
7:30 – 11:00 TASH Conference Registration
7:45 – 5:30 Club TASH Day Care/Youth Activities
8:00 – 5:00 TASH Exhibit Hall Open/Job Fair
8:00 – 3:15 Conference Sessions and Poster Presentations

3:30 – 5:45 Plenary Session and Awards
5:00 – 6:30 No Host Reception
8:30 – 10:00 Celebration of song

Saturday, December 13, 1997
7:30 – 9:30 TASH Conference Registration
7:45 – 2:00 Club TASH Day Care/Youth Activities
8:00 – 2:00 TASH Exhibit Hall Open
8:00 – 2:00 Conference Sessions
8:30 – 3:00 Full-Day Special Session: "Teaching Students with Significant/Multiple Disabilities in Inclusive General Education Settings"

1997 Conference Social/Special Events

Wednesday Evening, December 10, 1997
Opening Reception in the Exhibit Hall
5:00 P.M. - 7:00 P.M.
Welcome to all for the opening of the 1997 TASH Conference! Light snacks will be provided, with the opportunity to purchase beverages. Be first in line to see the incredible exhibits, and meet new and old friends.

Thursday Evening, December 11, 1997
5:00 P.M. - 6:30 P.M.
Sexual Orientation Interest and Action Group Hospitality Hour

5:00 P.M. - 6:30 P.M.
TASH No Host Reception

Friday Evening, December 12, 1997
5:00 P.M. - 6:30 P.M.
TASH No Host Reception

8:30 P.M. - 10:00 P.M.
Songs of Liberation and Community
Convened by Mara Sapon-Shevin and Mayer Shevin

"We Shall Not Be Moved"; "Ain't Gonna Study War No More"; "De Colores"; "We Shall Overcome"

Songs have always been a way that people struggling for their rights have stayed connected, kept their spirits up, and shared the stories of their struggles with the rest of the world. The Civil Rights' Movement, The Women's Movement, the movement for Gay Liberation and the Disability Movement have all produced wonderful songs. Join us for an evening of songs celebrating human spirit and solidarity. Singers and musicians from the Boston area will be joining TASH members to share their songs. Come to sing, listen, and share — this is an opportunity for everyone to participate — non-musicians and listeners most cordially welcome!

BEST COPY AVAILABLE

The NIDRR Research and Training Center's
NATIONAL BEHAVIOR MANAGEMENT

CONFERENCE

Positive Behavioral Support

September 19 - 20, 1997
University of California, Santa Barbara

Featured Speakers Include:

Dr. V. Mark Durand

Dr. Robert Koegel

Dr. Jacki Anderson

Dr. Aubyn Stahmer

Ursula Markey

H. R. Turnbull III,
LL.BJ.D., LL.M

Dr. Glen Dunlap

Dr. Ann Turnbull

Dr. George H.S. Singer

Dr. Edward Carr

Dr. Robert Horner

Dr. Paul E. Touchette

The Research and Training Center Conference on Positive Behavioral Support was formed as a direct response to the need for melding the values of dignity, normalization, deinstitutionalization, and individualization with the science of behavior analysis. The Research and Training Center is an NIDRR federally-funded project to develop and disseminate strategies that meet this need. Strategies being developed include techniques for assessing behavior problems, behavioral programming, promoting the generalization and maintenance of behavior gains, and training and implementing the treatment technology in school and community settings.

For more information contact: Dr. Robert L. Koegel, C/C/S Psychology Program,
Graduate School of Education, University of California, Santa Barbara, CA 93106-9490
email: jharr@education.ucsb.edu
http://www.education.ucsb.edu/~doniel/conference1.html

TASH TECH Pre-Conference Full-Day Seminars

TASH Techs are optional full day pre-conference seminars that offer opportunities for in-depth exploration of important topics. See the registration form on page 33-34 for information on fees and registration. Space is limited.

T1 Policy and Systemic Issues Regarding Performance and Supervision of Paraeducators and Direct Support Professionals

Patricia Mueller, Anna Lou Pickett, Amy Hewitt

Participants in this TECH will receive information that will enable them to more effectively build and sustain teacher-paraeducator teams. Topics to be addressed include distinctions in teacher-paraeducator roles; paraeducator skills and competencies; the role of teachers as supervisors of paraeducators; and resources.

T2 Inclusive Classrooms as Total Learning Communities

Mara Sapon-Shevin, Mary Fisher, Lucille Zeph

"Best practices" in general education - multilevel teaching, multiple intelligences, portfolio assessment, integrated or thematic instruction, cooperative learning and community building, are consistent with, and supportive of, the efforts to include students with significant disabilities. Critical elements supportive of the inclusion process will be discussed.

T3 Seeing Competence: Challenging Our Deficit Approach to Understanding and Supporting Individuals with Autism/Mental Retardation and Other Communication, Movement, and Behavior Challenges

Anne Donnellan, Phillip David Zelazo, Margaret Bauman, Michael J. Solomon Weiss, Martha Leary, Karen Strandt-Conroy, Sally Young, Madeline Hafner, Jean Hauser, Victoria Moerchen

Current models of assessment and support emphasize deficits rather than assume competence. The assumption and misunderstandings behind these deficit approaches will be discussed, as well as newer ways to assess, support, and communicate with labeled individuals.

T4 Public Schools and the Americans with Disabilities Act (ADA)

Kathy Gips, Melissa Marshall

Confused about school districts' responsibilities under the ADA and the ADA's relationship with Section 504 and IDEA? You are not alone. The requirements and gray areas of the law will be clarified.

T5 Curriculum Modification and Communication Supports TOGETHER in the Inclusive Classroom

Cheryl Jorgensen, Rae Sonnenmeier

Participants will practice techniques for analyzing opportunities for learning and communication in several general-case regular classroom situations, and for planning curriculum modification and communication supports that promote full participation. Target audience: teachers and communication specialists who work at the preschool – high school level.

T6 Specific Strategies to Support Friendships and Community Connections for People With and Without Disabilities

Angela Novak Amado

Stories, slides and specific "How To" strategies will be presented about how to support relationships with non-disabled community members. Lessons successfully used in residential, vocational, urban and rural areas, including individuals who have been labeled as having significant disabilities will be presented.

T7 Including Students with Disabilities as Fully Participating Members of the High School Community

Carol Tashie, Mary Schuh, Susan Shapiro Bernard

Why students with disabilities should spend their high school career with all peers, and strategies for overcoming obstacles that cause students to spend time away from typical peers will be discussed. What students should be learning in classes; after-school; weekends; and the transition to jobs will be presented.

T8 Inclusive Classrooms: Accessing the Opportunities of Whole Class Instruction

Christine Salisbury, Ginger Joyce, Toni Strieker, Deborah Tweitt-Hull

Emphasis is on how to adapt general education units such that whole class instruction occurs and teachers are kept from preparing and implementing separate lessons for students with unique learning needs. Information on how to keep the curriculum, instruction, and assessment flexible, meaningful and challenging to all students will be included.

T9 Preparing Teachers for Inclusive Schools: Strategies for Change within Higher Education

Gail McGregor, Dianne Ferguson, Alison Ford, Beverly Mattson

This session is designed to engage individuals working in higher education in discussion and action planning around preparing teachers to work in inclusive schools. Efforts to change current practices at multiple levels: within individual classes; within departments; cross-departments; cross-universities; and at the state level will be highlighted.

T10 Assistive Technology: From Policy to Reality

Katherine Inge, Karen Flippo

Assistive technology (AT) is a powerful force for inclusion of people with disabilities in schools, businesses, and communities. This session provides a comprehensive evaluation of AT policy; policy implementation; funding of technology; and observations regarding the challenges that individuals are facing finding jobs and making needed adaptations in the workplace.

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TASH TECH PRE-CONFERENCE FULL-DAY SEMINARS

continued from page 9

T11 Homeownership: A National Initiative

Jay Klein , Marcie Goldstein, Judith Snow, Joe Wykowski

People with disabilities are often not afforded basic choices about where they live and are amongst the most underserved group in the mortgage industry. This session is designed to provide individuals, families, lenders and professionals with strategies used by local coalitions throughout the United States to help individuals to own their homes.

T12 From Paternalism to Reciprocity: Putting "A Credo of Support" into Daily Practice

Mayer Shevin, Nancy Kalina

In their videotape " A Credo for Support," Norman Kunc and Emma Van der Klift describe a basis of connections that are not hierarchical social roles of "expert," client, "guardian, "etc.; rather a relationship based on respect, common humanity, and shared membership in each others world. There are still many questions when trying to implement this commitment. This session will provide a setting to frame and struggle with the questions.

T13 Making Meetings Matter

Marsha Forest and Jack Pearpoint

Make Your Meetings Matter. Practical and usable tools for running efficient, effective, creative and meaningful meetings anywhere & everywhere for all organizations. Everyone faced with running a productive meeting is encouraged to attend.

T14 Changing a Human Service Agency

Jeff Strully, Tara Asai, Patricia Fratangelo

This pre-conference session will focus on three different agencies that successfully converted all of their services to individualized, personalized, and valued supports. The session will provide specific strategies, methods, insights, reflections and stories on how to change the way you "do business."

T15 The Process of Positive Behavioral Support with Families in Natural Contexts

Bobbie Vaughn, Kathy Ben, Glen Dunlap, Joseph Lucyshyn

This session is for families of children with disabilities who display problem behaviors, and for professionals who offer behavior support to families. Four concepts will be emphasized: family-professional partnership; lifestyle change/outcomes; comprehensive assessment, functional assessment, and family ecology assessment; and contextually appropriate, multi-component support plans.

T16 Family-Centered Approaches in Early Childhood

Susan Yuan

Families of young children with disabilities have been well included in planning, but how family-centered are those plans? This workshop invites participants to explore philosophy, consider real cases and practice strategies to meet the needs of the whole family.

T17 Implementing I.D.E.A. Following Reauthorization: Implications for Students, Families, and Schools

Kathy Boundy, Eileen Ordover, Frank Laski, Tom Gilhool, Judy Gran

The Individuals with Disabilities Education Act (IDEA) is a 22 year old civil rights law that ensures a free and appropriate public education for all children. In 1997, the 105th Congress voted to make significant changes to the law. Join several of TASH's legal experts as they discuss the significance of the changes, the current status of the new law, and specific strategies for ensuring adequate implementation and enforcement.

T18 Supporting Students with Autism/ PDD in Regular Classrooms

Barbara Cutler, Barbara Domingue, Herbert Lovett

This session will offer an understanding of Autism/ PDD and the implications for practical strategies and supports for students in regular classrooms.

T19 Grassroots Advocacy

Michael Auberger

Join Mike, TASH Board member and the founder of ADAPT, the group that defined "in your face" advocacy, to discuss strategies for moving systems without compromise.

TC – TASH Chapter Leadership and Development Day

This free session is offered to TASH Chapter Officers, chapter members, and people interested in forming a TASH Chapter. An interactive day is planned on chapter organization, administration, fundraising, membership drives, grassroots organizing and legislative action. You must register in advance. Lunch will be provided, and attendees will receive 25% off regular conference registration.

* * *

Governmental Affairs Strand

(Thursday-Saturday)

Join us throughout the conference as we focus on the critical governmental and public policy issues affecting people with disabilities and their advocates.

We will follow last year's successful model, which included information sessions followed by discussion, needs assessment, prioritization and action planning for the coming year.

Topics will include IDEA 97 Regulations, Anti-aversive legislation, Implementing and Enforcing IDEA, SSI-Kids, Medicaid, Welfare Reform, Managed Care, Vocational Education, SSA, Employment, Personal Assistance and Assisted Suicide. Also look for how-to sessions on "Lobbying, Grass Roots Organizing, the Legislative Process, Getting Involved in Local Politics and much, much more…

IN-FOCUS STRANDS

In-Focus Strands are simply a series of sessions on a particular topic(s) that have been scheduled one after another in the same room. Other sessions on that same topic may be scheduled throughout the conference. There are not In-Focus Strands on every topic that will be presented at the 1997 Conference.

Below is a list of the strands for this year. The length of the strand is listed under the title. Specific sessions that will be held in that strand are listed in the tentative session schedule all through this Newsletter, and are identifiable by the code listed for each strand. For example (R) for sessions in the research strand. You may choose to attend all of the sessions within a strand, or pick and choose certain sessions.

Current Issues in Research and Practice

Thursday, December 11, 1997 through Saturday, December 13, 1997

Coordinated by Norris Haring

TASH has always been and continues to be on the cutting-edge of research which has demonstrated effectiveness in policy and practice in issues around disability. This year we continue the effort to link research and intervention methods. All through out the conference you will find sessions that will help define the future in many areas of research. Look for sessions marked with an (R) for research related content.

Code For This Strand in Session List: (R)

Advocacy

Thursday, December 11, 1997 and Friday, December 12, 1997

This strand focuses on cutting-edge issues relating to self-advocacy. Look for several sessions by nationally known self-advocates, including SABE (Self Advocates Becoming Empowered). Strategies and tools for empowering individuals and moving systems will be addressed.

Code For This Strand in Session List: (A)

Children Who Significantly Challenge Schools But Who Do Not Have Significant Disabilities

Saturday, December 13, 1997

Coordinated by Linda Rammler and Debbie Gilmer

This strand will focus on hot topics related to children who do not have labels of significant disabilities as typically focused on by TASH, but who challenge the system and require additional supports in the areas of family support, inclusive education, positive approaches. A variety of sessions from student, parent, transdisciplinary team members, and others from around the country involved in the issue will be included. The following sessions and others will be part of this strand. Specific times to be announced:

Bridges to Inclusion

Cecilia Gandolfo, Kathy Manganaro

Empowering Community Participation & Self-Determination

Denise I. Ferrara, Victoria Crosby, Fredda Faye, Sheryl Goodine

Code For This Strand in Session List: (CH)

5th Annual Community Living Gathering

Host: Lynda Baumgarder

The Gathering is a place for everyone to create a forum in which interests and concerns relating to community living can be heard. This is your chance to get together with others and discuss the burning issues that are important to you. Past year's agendas have included such topics as: circles of support, multicultural issues, roommates, family issues, employment, support issues, and much more. Come join in and learn from each other in a friendly and supportive atmosphere. A specific agenda will be developed on Thursday during the opening celebration. The opening will be at 9:00 AM and will be with Herb Lovett, Judith Snow, and Jay Klein. The Gathering runs throughout the entire conference - come and go or stay all day! Everyone is welcome to participate.

Community Living Strand

Thursday, December 11, 1997 through Saturday, December 13, 1997

Host: Joe Wykowski

The Community Living Interest and Action Group will be convening a strand of presentations throughout the conference. All sessions will be next door to The Gathering. The presenters in the strand will be available to move next door and continue conversations in The Gathering.

Code For This Strand in Session List: (CL)

Research on Curriculum in Inclusive Education Settings

Saturday, December 13, 1997

Coordinated by Diane Ryndak

This strand will focus on providing an overview of a variety of cutting-edge information relating to successful curriculum and instructional strategies in inclusive settings. Conceptual models and practical strategies will be emphasized.

Code For This Strand in Session List: (CUR)

Supporting Young Children and Families in Schools and Communities: Perspectives, Practices, and Issues

Thursday, December 11, 1997 through Saturday, December 13, 1997

Coordinated by Elizabeth Brennan and Elizabeth Erwin

This strand, sponsored by the Early Childhood Interest and Action Group, will focus on improving the quality of services, supports, and experiences in natural environments for young children with severe disabilities and their families.

Code For This Strand in Session List: (E)

Employment Strand

Thursday, December 11, 1997 through Saturday, December 13, 1997

Coordinated by Michael Callahan, Patricia Rogan, and David Mank

Join us again this year as we highlight over 30 presentations covering hot issues in the employment of people with significant disabilities. Topics will include natural supports, choice, conversion, individualized planning, and much more!

Code For This Strand in Session List: (EMP)

Family Strand

Thursday, December 11, 1997 through Friday, December 12, 1997

Coordinated by Barbara Buswell

This strand is sponsored by the Family Interest and Action Group and will provide a series of cutting-edge sessions empowering to families, and valuable to both families and professionals. Look for great sessions throughout the conference on family issues. The following sessions and others will be part of this strand. Specific times to be announced:

12/11/97

Cracker-barrel on Sibling Issues (FAM)

Sister Act (FAM)

Nancy Verderber, Katie Stollhans

Working with School Personnel to Establish an Effective Planning Team for Your Child (FAM)

Linda Davern

Continued on page 12

continued from page 11

Loving Lisa - A Family's Story of Collaborative Support (FAM)
Ann P. Monroe-Baillargeon, Emma Baillargeon, Joseph Baillargeon, Martha Baillargeon, Peter Baillargeon, Lisa Monroe

12/12/97
Sleep Better! Improving Sleep for People with Special Needs (FAM)
V. Mark Durand

From Rhetoric to Reality: One Family's Experience (FAM)
Sue Lehr, Ben Lehr, Bob Lehr, Jesse Cavender

Code For This Strand in Session List: (FAM)

Higher Education and Preservice Teacher Preparation

Thursday, December 11, 1997 and Friday, December 12, 1997
Coordinated by Diane Ryndak
The Higher Education and Preservice Teacher Preparations Strand includes sessions related to restructuring preservice personnel preparation, cross-discipline preparation efforts, and university-school partnerships to facilitate change and/or preservice instruction. There are also many sessions throughout the conference on other issues relating to personnel preparation.

Code For This Strand in Session List: (H)

Leisure and Recreation Across the Life Span

Thursday, December 11, 1997
Coordinated by Cynthia Burkhour and Linda Heyne
The Leisure and Recreation Strand will explore current issues in promoting lifelong leisure for people with disabilities. These issues include playground accessibility, promoting friendship, community inclusion, and meeting needs relating to cultural diversity.

Code For This Strand in Session List: (L)

Linking Inclusive Education, Systems Change, and School Reform: Lessons Learned from Policy, Research and Practice

Thursday, December 11, 1997 through Saturday, December 13, 1997
Coordinated by Anne Smith
Inclusive education means many things to many people -"top down" and "bottom-up" school change efforts have taught us that inclusion is "slippery" depending on it's meaning, not just on a description of events or conditions, but on the meaning it holds for those involved in the experience. This three-day strand will feature people from across the United States who are pursuing inclusive education, systems change, and school reform from policy, research, and practice perspectives. We know that strategies to promote inclusive schooling are vitally connected to the context and culture of the school environments. TASH members believe that inclusion can further systemic education reform efforts to make schools more pedagogically responsive to the natural diversity found in our school population, by creating schools where both adults and children work together to support active learning and membership for all students.

Code For This Strand in Session List: (ER)

Management Issues

Thursday, December 11, 1997
This full day strand highlights several issues key to organizations who are providing quality and inclusive services. Look for topics such as organizational structures, change, and leadership skills.

Code For This Strand in Session List: (M)

Multicultural and International Issues

Thursday, December 11, 1997 through Saturday, December 13, 1997
Coordinated by Lynda Baumgarder, Ming-Gon John Lian, and Walter Szyndler
The Multicultural Interest and Action Group is planning a variety of sessions throughout the conference that will include information on issues relating to multicultural and international issues. The group also strongly encourages all presentations throughout the conference to include perspectives from diverse backgrounds and nationalities, as multicultural issues are involved in, and central to, all aspects of what we do as community builders, educators, professionals, and friends.

Code For This Strand in Session List: (IM)

Strategies for Building and Sustaining Supervisor and Paraprofessional Teams

Friday, December 12, 1997 and Saturday, December 13, 1997
Coordinated by Anna Lou Pickett and Patricia Mueller
This strand is sponsored by the Paraeducator/Paraprofessional Interest and Action Group. Despite increased reliance on paraprofessionals in more complex and demanding roles, little attention is being paid to a broad range of issues related to their performance as members of the educational and adult services community. This strand will focus on policy questions, training issues, and infrastructures that support effective utilization of paraeducators and direct support professionals.

Code For This Strand in Session List: (PAR)

Innovative Practices in Positive Behavioral Supports

Thursday, December 11, 1997
Coordinated by Richard Amado and Fredda Brown
This strand is sponsored by the Positive Approaches Interest and Action Group, and will focus on innovative practices in the development and implementation of positive supports in inclusive settings.

Code For This Strand in Session List: (P)

Sexuality and Sexual Expression

Thursday, December 11, 1997 through Saturday, December 13, 1997
Coordinated by Ann Heler
Sexuality and sexual expression are a natural part of each of our lives. These sensitive and critical issues require awareness, respect, and commitment to ensure all people have the ability and the information to act upon their choices and interests. There will be several dynamite sessions scheduled throughout the conference. The Interest and Action Group will hold a hospitality hour Thursday evening and an open forum on sexual orientation issues Saturday morning. Look for informational notices posted in the registration area at the conference.

Code For This Strand in Session List: (S)

Urban Education Strand

Friday, December 12, 1997
Coordinated by Nancy Zollers, Alison Ford, Gwen Benson
This strand will include presentations and conversations about issues affecting inclusion in the cities. Join us for a discussion on what works and what the challenges are in urban schooling.

Meeting the Special Health Care Needs of Children at Home and School

Friday, December 12, 1997 and Satruday, December 13, 1997
Coordinated by Donna Lehr
This strand is sponsored by the Special Health Care Needs Interest and Action Group. Sessions will focus on practices necessary for school inclusion of students with special health care needs. Methods of assuring the safe provision of health care services and appropriate educational programs will be highlighted.

Code For This Strand in Session List: (SPH)

EXECUTIVE DIRECTORS - CONNECTICUT & DELAWARE

COMMUNITY SYSTEMS, INC., of Torrington Connecticut and Newark Delaware seek new EXECUTIVE DIRECTORS.

CSI CT is a nine year old company providing residential and vocational opportunities to 70 persons with Developmental Disabilities in small group settings, individual apartments, vocational enclaves, and 3 ICF/MRs. Most often the persons we serve have additional challenges which may include mental illness, significant medical conditions, and sensory impairments. CSI DE is a three year old company supporting 75 persons with disabilities in similar community settings.

CSI seeks seasoned professionals, at least Masters prepared, or an RN, with a minimum of ten years of experience, five of which must be in the direct provision of services to people. Our Executive is the clinical leader, but operates in a "bottoms Up" environment where the line staff are recognized as the keys to achieving our mission:

"Helping people with disabilities to find happiness in their homes, lives and communities".

CSI offers a competitive compensation package and a willing, dedicated staff. Please send resume/vitae and letter of interest to:

Executive Search - Connecticut
Community Systems Inc.
295 Alvord Park Road
Torrington, CT 06790

Executive Search - Delaware
Community Systems & Services Inc.
8301 Greensboro Drive, Suite 440
McLean, Virginia 22101

CSI actively supports workplace diversity. EOE/AA/M/F/D/V

The University of Utah Master of Science Degree Program

COMPREHENSIVE BEHAVIOR SPECIALIST

The Department of Special Education at the University of Utah is pleased to announce a new interdisciplinary program to promote the professional development of educators and community service providers who work with children and youth with significantly challenging behavioral needs. The focus of this program are those professional competencies (i.e., functional assessment/analysis, program development and implementation, team facilitation, training and technical assistance, and evaluation) needed to provide positive support to students in neighborhood schools and other community settings.

Graduate students will apply each of these skills across the different levels of service planning encountered by professional team leaders or consultants -- individualized support, classroom-based and/or school-wide systems, and multi-agency and community-based planning.

The Department is now recruiting interested students for admission for the 1997-98 and 1998-99 school years. Stipends and tuition waivers are available for eligible candidates. For more information on the program or the admissions process, contact either Dr. Richard Kiefer-O'Donnell (801-581-3080), Dr. Rob O'Neill (801-581-3989), or Dr. Woody Johnson (801-585-9183). To obtain application materials, contact Patty Davis (801-581-4764).

—Special Sessions—

These cutting-edge sessions are in addition to the regular 1 or 2 hour/15 minute sessions scheduled throughout the conference.

12/11/97 8:00-11:30
"Walking the Talk" Examining Our Teaching Practices in the University Classroom
Barbara Ayres, Deb Hedeen
This session provides an opportunity for individuals involved in teacher preparation to examine their course content, methods and goals. Examples of cooperative group activities, problem-based learning, and the use of multiple intelligence theory in the university classroom will be presented. Participants will be encouraged to bring course syllabi, sample activities, assignment descriptions, and examples of alternative assessment strategies.

12/12/97 11:45-3:15
Back to Basics: Sexuality, Disability, and Abuse
David Hingsburger
So just what do you know about sexuality and disability? This session will allow participants the opportunity to discuss the major myths about sexuality and disability. Probably more than any other group, people with disabilities have been subject to policies and practices built on fear rather than fact. This interactive session will challenge, educate, and entertain.

12/12/97 8:00-11:30
Activities or Subject-Based IEP's for Inclusive Classrooms
Linda Rammler, Robin Wood
Participants will learn an alternative approach to IEP development for inclusive classrooms, practice applying the six steps with technical assistance from the presenters, and share experiences for feedback and advice.

12/12/97 9:15-11:30
Building Circles of Friends
Marsha Forest, Jack Pearpoint, Judith Snow, Janet Thomas, Bryce Thomas, Joel Hollands, Jonathan Hollands
Building Circles of Supports/Friends is both complex and exciting. It is a life long endeavor that has neither a recipe nor a simple answer of "what to do." This unique session will offer the perspective of both adults and children who are involved in "living" the circle. We will all share what we have learned to do and not to do. This will be an inspiring, practical, helpful, challenging, and meaningful session. Everyone is welcome!

12/12/97 10:30 - 12:45
Issues of Peace
Alan Berger
Carve two hours (or some part thereof) of peace out of your day to take part in this East/West exploration of peace activisim and contemplation. Each half hour will bring a different perspective on peace issues. Brought to you by the Peace Interest and Action Group. On yeah, did we mention the food? (non-violent of course!).

12/12/97 10:30-2:00
Implementing Positive Supports in the Community: Solving the Real Issues
Rick Amado, Fredda Brown, Tim Knoster, Rob O'Neill, Jeffrey Sprague
There a variety of effective and powerful strategies designed to address the needs of individuals who display severe challenging behavior. As we apply these strategies in communitiy settings within the context of 24 hours a day of real life, we are faced with many challenges. This panel will address the challenges that now face the field in implementing positive supports in community settings under a variety of conditions typical of community life.

Project TechLink

Linking Educators and Parents to Transition Best Practices through Computer Technology
http://www.vcu.edu/rrtcweb/techlink

Project Tech-Link offers the following opportunities:

- Develop resource and support networks with other individuals across the World Wide Web using TechLink's chat room, bulletin board, and e-mail features.
- Review and obtain resource information from the "Information and Resource" files.
- Complete courses related to a variety of secondary issues.

Upcoming Courses:
Course 1: ***Whose Life is it Anyway? A Look at Person-Centered Planning & Transition*** (Sept. 15 - Oct. 20, 1997)
Anne Malatchi & Katherine Inge featuring a special chat session with Jack Pearpoint & Marsha Forest
Course 2: ***Community-based Instruction*** (Jan. 5 - Feb. 9, 1998)
Katherine Inge, Sherril Moon, & Amy Armstrong
Course 3: ***Transition from School to Work: Supported Employment as a Post-School Outcome*** (April 6 - May 4, 1998)
Paul Wehman, Katherine Inge, Amy Armstrong, Mike Barcus, Vicki Brooke, & Howard Green

Project Staff:
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Virginia Commonwealth University
Rehabilitation Research and Training Center on Supported Employment
PO Box 842011 • Richmond, VA 23284-2011 • 804-828-1851

VCU is an equal opportunity/affirmative action institution. If special accommodations are needed, please contact Katherine Inge at 804-828-1851. TechLink is funded by the U.S. Dept of Education, Grant # H086U60038.

THURSDAY, 12/11/97
8:00-9:00

The Right to Communicate
Harvey Lavoy, Ellen Berrings, Larry Bissonette, Pascal Cravedi-Cheng, Sarah Hathaway, Tracy Thresher

Partnerships to Promote Employment
Roger Bailey, Robert Young

Students First: Parents as Partners in the Special Education Process
Mary M. Fitzgerald, Marlene Johnson

Supported Education and Performance Assessment: A Process to Increase Collaboration and Improve Inclusion (R)
Joel Arick, Pat Jackson

Desktop Computers as an Instructional Resource in Preparing Educators in Significant/Multiple Disabilities
Barbara Ludlow, Michael Duff

Believe in Yourself: The Road to Becoming a Self-Advocate
Margaret Stout, Sheri Glasser, Patricia Sullivan

Instructional Practices As Natural Supports to All Learners
Amy Kuhns Bartlinski, Amy Donnelly

Teach Them Well, and They Will Lead the Way: Building an Environment and Creating Activities that Foster Community for Young Learners
Russell Johnston, Robin Fabiano, Kim Glaser, Carolyn Kaufman, Jan Lewis, Mollie Moran

Abuse and Neglect of Individuals with Developmental Disabilities
E. Wayne Crawford

Friendships of Children with Deaf-Blindness: Themes from the Parents' Viewpoint
Nancy Sall

Using Positive Behavioral Support for All Students in the School (POS)
Edwin Helmstetter, Chris Curry

Conquering America's Worst Fear
Becky Troyer

Identifying Critical Behaviors that Promote Social Interaction in High School Settings (R)
Carolyn Hughes, Sarah E. Pitkin, Michael S. Rodi

Related Services in an Educational Setting: Creating the Vision
Christine E. Pawelski, Denise L. Ferrara, Jeanette Glover

Alternative Portifolios in Kentucky: A Method for Promoting Grass Roots Advocacy
Phillip G. Wilson, Linda Flynn-Wilson, Pat Gilmer

Early Intervention: Experiences of a Young Child with Autism (EC)
Valerie Lava

Meet The Hartmans & Their Expert Witness: Just Another Family From The Neighborhood In Federal Court
Patrick Schwartz, Joe Hartman, Mark Hartman, Roxanna Hartman

AAC Programming to Support Language, Literacy and Social Interaction
Martha Boose, Jennifer Bourque

8:10-8:30
Systems Change and Policy (ER)
Lisa Lawter

8:00-8:15
Introduction to Strand: Issues in Leisure and Recreation (L)
Linda Heyne

8:15-9:00
Youth in Recreation: Personal Reflections (L)
Erin Burkhour, Joshua Burkhour

8:30-9:45
School Reform: Lessons Learned From Policy, Research and Practice (ER)
Anne Smith, Dianne Ferguson, Doug Fisher, Brian McNulty, Christine Salisbury

THURSDAY, 12/11/97
8:00-10:15

Building Linkages Between Assessment and Instruction: Outcomes-Oriented Strategies for Individualizing General Education Curricula
Jan Writer, Terry Murphy

Who Belongs Here? Wrestling the Beast Within (CL)
Ann Marie Campbell, Estelle Bailey, Sharon Denomme, Ruth Frank, Kim Koita, Barbara Prince

Enhancing Natural Supports: Instructional and Organizational Issues in Employment Support (EMP)
John Butterworth, Ilene Asarch, Noreen Donnelly, Sherill Faris

The Inclusion of a 17 Year Old Young Man with Autism into a Regular Education Program Using Facilitated Communication
Brenda Silva, Kenneth Affonce, Kenny Affonce

Real Friendships: Supporting People with Disabilities in Reciprocal Relationships
Susannah Joyce

Organizational Structures That Work (M)
Karen Lee, Carol Beatty

THURSDAY, 12/11/97
9:15-10:15

Getting a Handle on Teamwork Run Amuck - Knowing Whom to Ask for Support, When and How
Michael Giangreco, Susan Edelman

A Multi-State Evaluation of Parent To Parent Self-Help Programs: Participatory Action Research (R)
George Singer, Connie Ginsberg

Systems Change: SEA Strategies to Support Inclusive Education
Kerry Ottlinger, Gwen Beegle, Carol Dermyer, Mike Remus

Methods of Preference Assessment Using Nonsymbolistic Communication (R)
Diane Browder, Sharon Lohrmann-O'Rourke

Two Steps Forward, One Step Back: Special Education Teacher Preparation Reform (H)
Anne Bauer, Thomas M. Shea, Mary E. Ulrich

Integrating the Arts: Supporting Inclusive Practices with Drama
Doug Eicher, Ric Averill

Beyond the FC Debate: Supporting the Use of Facilitated Communication in Supported Employment (E)
Nancy Kalina

Strategies to Fully Include Students with Multiple Disabilities in General Education Settings
Joanne Eichinger, June Downing

Beyond Simulations: Authentic Activities for Promoting Awareness of the Disability Experience
Paula Neville

Theory and Research on Behavioral Escalation: Practical Implications (P)
Richard W. Albin, Smita Shukla

How/Why Do Teachers Choose the Teaching Strategies They Use? (R)
Edward Carter, Pamela Green, Dayna Hutchins

Assessment and Planning For Curriculum and Instruction Using the MI Theory
Mary A. Falvey, Jacqueline Thousand, Alice Udvari-Solner

Advocating for Access to Parks and Playgrounds (L)
Cynthia Burkhour, Tip Ray

Changes in the Use of Literacy When Included After Ten Years in Self-Contained Special Education (R)
Diane Ryndak, Andrea Morrison, Lynne Sommerstein, Michelle Sommerstein

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THURSDAY SESSIONS

continued from page 15

Utah Distance Education Project to Prepare Teachers of Students with Significant Disabilities
Martin Agran, Richard Kiefer-Kdonnell

THURSDAY, 12/11/97
9:15-11:30

Current Issues in Early Childhood (EC)
Pip Campbell

Stories of Inclusion in Work, Community Service and Post-Secondary Education
Cynthia Thomas, Tony Bonfiglio, Erin Herlihy

Lift Every Voice: A Leadership Training Package for Self-Advocates (A)
Tia Nelis, Liz Obermayer, Nancy Ward

All Students Can Learn Together with Just a Few Ideas
Peggy Locke, Helen Canfield

THURSDAY, 12/11/97
10:30-11:30

Creative Employment Services (E)
Diane Browder, Edward Grasso, Tim Minarovic

Italy: Of Course We All Fit In. The Alternative is Barbaric! (IM)
Carol Berrigan

We Can Do It Better Together: Merging Preservice Training Programs in Elementary and Special Education (H)
Susan DeLuke, Maureen Gillette

Educational Accountability for All Students
Jacqui Farmer-Kearns, Sarah Kennedy, Harold Kleinert, Patricia Murphy

The Sexual Knowledge, Attitude and Feelings of People with Disabilities, Staff, and Familes in Austria (S)
Wolfgang Plaute, Karyl Resnick

Personnel Preparation Through Web-Based Instruction
Nella B. Anderson, Jill Hampton

Vision Shared: Building Regional Capacity to Support Inclusion
Margaret Coady, Marilyn DeJean, William R. Sharpton

A Comparision of Development and Social Competence for Students Enrolled in Inclusive and Segregated Programs (R)
Mary Fisher, Stacey Minondo, Anne Smith

The Meaning of Positive Behavior Support (P)
Linda Bambara, Ophelia Gomez, Freya Koger, Sharon Lohrmann-O'Rourke

What Parents and Teachers Want in Their Communication Process
Dayle A. Upham

First Jobs (EMP)
Norciva Geddie Shumpert

California's Community Expansion Efforts: Experiences, Satisfaction, and Outcomes for 2700 People Who Have Moved in Three Years
James W. Conroy

Collaboration for Success
Meredith Lowman, Clarice Custer, Sue Hale

Therapeutic Recreation: A Person-Centered Approach (L)
Bob Cipriano, Sandy Ammirato

School Improvement: Tactics for Embedding Inclusion in General Education Reform (ER)
Caroline Moore, Mary Dalmau, Dianne Ferguson

THURSDAY, 12/11/97
10:30-12:45

Consent Issues and People With Developmental Disabilities (S)
Matt Sturiali

Home At Last: Lifestyle Perspectives of Person-Centered Supports (CL)
Paul Malette, Jeff Moulins, Lynda Perry

A School for Everybody: Using Disability Awareness and ADA Training in Fostering an Inclusive Environment
Melissa Marshall

Leadership for a Changing World (M)
Jane Cornbleet, Lynne-Marie Duncan

Accomodating Diversity: Curricular Issues
Melody Nay, Harriet Cramer

Promoting Alternative, Integrated Day Activities
Pam Walker

THURSDAY, 12/11/97
11:30-12:30

Supporting School Improvement Process (ER)
Elizabeth Kozleski, Robin Brewer, Terri Rogers Connolly, Janet Filbin, Beth Schaffner, Janell Sueltz

THURSDAY, 12/11/97
11:45-12:45

Families' Experiences of Finding Appropriate Day Care (EC)
Monimalika Day, Ruth Coates

Predicting Factors that Result in the Social Integration of Supported Employees (E)
Janis Chadsey

Cost Saving and Improved Quality of Life as a Function of Volunteer Services in Supported Living
Kathryn Edwards, Maryam Abedi

Now That Everybody's Here What Do We Do? Facilitating Individual Transition Planning for Students with Severe Disabilities
Pamela Wolfe

Passages: Issues in Self-Determination
Bud Cooney, Bob Aleaxander, Janet Duncan

Multi-Method Research on Positive Behavior Support with Families - The Family Network Project (P) (R)
Bobbie J. Vaughn, Glen Dunlap, Lise Fox

Taking Charge of My Life (A)
Barbara Cutler, Robert Cutler, Gunnar Dybwad, Herb Lovett, Darcey O. Perry, Mark Powell, Larry Tummino

Independence and Empowerment Through Augmentative Communication (E)
Erin Herlihy, Tony Bonfiglio

Family Support and Advocacy for Portuguese and Spanish Families (IM)
Adelina Perry, Esther Acevedo

Restructuring Higher Education and Key Issues with Restructuring Pre-Service Programs
Christine D. Templet, Carl Ferguson, Nancy Morris, Jimmie L. Matthews, William R. Sharpton

Getting to Know You: The First Steps Towards Community Membership
Jane Harlan, Peggy Holtz, Jennie Todd, Becky Troyer

Self-Advocates and Families Making Real Changes in Quality of Life
Suzanne Woolever, Mike Hanrahan, Steve Hurst

"It's ALL About Community!" Philadelphia's Public Awareness Initiative
Freda Egnal, Sandra Champion, Graham Gill, Jean Searle, Marianne Trainerl

Starting an Inclusive High School Program: A Step By Step Approach
Rosalind Vargo, Joseph Vargo

Alternative Assessment of Students with Intense Educational Needs
Sharon Lynch, Nella B. Anderson

Children With Disabilities: Newest Immigrants? (IM)
Cynthia Sutton

Facilitating Active Student Participation in Inclusive Settings
Jean Gonsier-Gerdin, Kathy Doering, Anne Hirose-Hatae, Julie Maier

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THURSDAY SESSIONS

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Preparing Teachers in Low Incidence Disabilities by Linking University Personnel Training Programs
Susan Bashinski, Nina Smith

WANTED: JUST ONE FRIEND! Developing and Supporting Circles of Friends for Young Adults with Disabilities (L)
Michelle Freid, Lynne Sommerstein, Michelle Sommerstein

A Feminist Approach to Mentoring University Students and Practicioners in Partnership with People with Developmental Disabilities
E. Ann Hughson, Shelley Kinash

THURSDAY, 12/11/97
1:00-2:00

Inclusive Practices to Promote Positive Learning Experiences for Young Children with Disabilities in NSW, Australia: The Early Learning Program (EC)
Nancy Butterfield

Working, Going to School, and Making Friends
Joanne Malloy, Steve Bernstein

Philosophy to Reality: Providing Services in an Era of Choices and Self-Determination
William Schofield

St. Anthony School Programs Post-Secondary Project: A Response to the Upper Age Limits of Inclusion
Kim Scanlon Lieb

A Case Study of Inclusion of Elementary Students with Significant Disabilities (R)
Steven R. Lyon, John Pryde

The 3A's: Strategies for Attaining Alertness, Arousal and Attention in Children with Significant Disabilities
Robin Greenfield, Gail Brown

Learning Across Cultures: International and Cross-Cultural Exchange (IM)
Pamela Block, Doreen McConaghy, Gloria Migneault, Darcy Oliveira Perry

Planning Progress vs. Planning Process
Margaret Cantey

Natural Supports: What Do We Know? (EMP)
David Mank, Patricia Rogan

Job Development for Families and Individuals: Don't Just Leave It to the Professionals (EMP)
David Hoff, Sue Cusack, Marty Gold

Inclusive Network of Kansas: Keeping Kansans Connected to Exemplary Education
Gwen Beegle, Susan Bashinski, Joan Houghton, Donna Wickham

From Shattered Dreams to Dream Catchers: The Journey Continues
Anne Malatchi, Kate McCoy, Harry McCoy, Mary Peterson, Mike Peterson

New Systems Change Management (M)
Stephen R. Hall

Developing Recreational Options for Persons with Disabilities (L)
Joanne Suomi, Rory Suomi

From Contingent Electric Shock to Community Living: One Man's Story (P)
Fredda Brown, Lisa Pitz, Fredda Rosen, James Velez

Enhancing Community Living of Culturally Diverse Individuals with Disabilities (IM)
Ming-Gon John Lian

Critical Issues in Curriulum for Students with Significant Disabilities
Sandra Alper, Martin Agran

Operationalizing Curricular Instruction
Donna Lehr, Patricia McDaid, Regis Miller

Center for Disability Leadership: Confronting Oppression in Disability Rights (A)
Carolyn LeJuste, Ian Engle, Tony Wong

Disability Humor: Moving Beyond That's Not Funny
Mara Sapon-Shevin, Robin Smith

Research as Practice/Practice as Research: An Innovative Approach to Co-Teaching Practice-Based Inquiry (H) (R)
Dianne Ferguson, Larry Irvin

Making Inclusion Work for Students with Fetal Alcohol Syndrome or Fetal Alcohol Effects
Linda Guest, Myrtle Pruden

1:00-1:50
Challenging Standards for All: Restructuring and Inclusive Education (ER)
Maria Timberlake, Betsy Enright

1:50-2:45
Legal Rights in Education Reform: Standards, Curriculum and Opportunities to Learn for All Students (ER)
Kathleen Boundy, Eileen Ordover

THURSDAY, 12/11/97
1:00-3:15

Creative and Successful Inclusive Classrooms: Instruction, Assessment, and Social Relationships
Kathy Gee, Nan Graham, Anne Jensen, Kimberly Strain

International Developments in Inclusive Education (IM)
Gunnar Dybwad, Marcia Rioux, Mark Vaughn, Nancy Zollers

MAPS and PATH: Creative Action-Oriented Tools for Inclusion
Marsha Forest and Jack Pearpoint

"I Want to Be on the Outside" (CL)
Kathryn Mazack, Jan Oliver, Angie Sharp

THURSDAY, 12/11/97
2:15-3:15

Discussion of Issues Around the Challenge of Social Inclusion as Children With Disabilities Approach Adolescence
Sue Manos, Carol Quirk

Can You See Me?
Karen Stevens, Colleen Barber

Inclusive Services in the Community
Colleen Santiago, Christina Piasecki, Tomas Santiago

Genetic Screening: Are Women Getting the Information They Need? (R)
Christy Roberts, Linda Parrish, Laura Stough

Early Childhood Crackerbarrel
Beth Brennan, Elizabeth Erwin

Wise People Travel to Discover ...Themselves
Michelle Rehm-Stauffer

Achieving Program Outcomes Without Losing the Person (M)
Michael Renner

The Community Support Skill Standards Partnership
Marianne Taylor, Valerie Bradley, Amy Hewitt, Julie Silver

Supporting Student Directed Career and Transition Planning
Kathy Osborn, Mary Held, Larry Schaaf

Changes in Quality of Life Among Users of Facilitated Communication
Donald N. Cardinal

A Prerequisite to Inclusion: Teachers with Good Critical Thinking Skills (H)
Pamela J. Gent

Biobehavioral Issues in Positive Behavioral Supports (P)
Craig Kennedy, Kim Meyer

Self-Advocacy for Self Advocates: A Leadership Guide (A)
Alan Kurtz, Jeff Saucier

The Individual Supports Identification System
Lyle T. Romer, Paul Froese

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THURSDAY SESSIONS

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Why Not the Y? Accessing Recreation in Your Community (L)
Susan M. Tufts, Maria Paiewonsky

Lessons Learned: Conversion From Sheltered Employment and Day Hab to Community-Based Employment (EMP)
Sheila Lynch-Fesko, John Butterworth

Lessons in Transition Partnerships: An Innovative School District/University Relationship
Dawn Hunter, Jan Mower

Capacity Interchange Project: Building Relationships and Sharing Expertise (IM)
Paula Sotnick, Vaunne Ma, Jean Whitney-Thomas

Gender Bias, Ethnic Bias, and Exclusion in Special Education (IM)
James W. Conroy, Tom Nerney, Barbara Ransom

Marketing is Everybody's Job (EMP)
Paula Johnson

Character Education: Teaching Children Self-Esteem through Fairy Tales and Alligories
Barry Rudner

Using Internet to Prepare Teachers about Inclusive Education
Jane Wortman

—Thursday Poster Sessions—

THURSDAY, 12/11/97 9:15-11:15

Using Family-Centered Play Sessions to Build Inclusive Environments
Anne Modler, Paulette Chaplin

"Together We`re Better"- Inclusive School Communities in Minnesota
Mary McDevitt Krajlic

Student Assistants: A Natural Support to Reinforce Speech/Language Techniques in a High School Environment
Nancy Dixon, Carolyn Auld, Janice Siebenhaar

Creating Caring Communities: Utilizing the Personal Learning Plan Model Within Inclusive Classrooms
Wes Williams, Carol Burdette, Tim Fox, Wayne Fox, Lauren Gillis, Kelly Leo, Janet Lockyer

Linking Functional Analysis Assessment to the Development of Behavior Support Plans for Individuals with Developmental Disabilities
Lora Heathfield, Robert H. Horner

Compiling a Home Medical Journal for Those With and Without Disabilities
Vicki Griffith

A Home of My Own: What's Happening in Louisiana
Charol Armand, Nancy Robertson

Results of National Data Collection Concerning Day and Employment Services for Individuals with Developmental Disabilities
Dana Scott Gilmore, John Butterworth, David Temelini

Building Community For All: Steps for Successful Inclusion of Children with Significant Disabilities
Pamela W. Holmdal, Patricia Hoey, Joan Ruberton

Issues In The Provision of Services For People With Dual Diagnosis of Mental Retardation and Mental Illness
James Sperry, Nancy Connolly, John Randall

THURSDAY, 12/11/97 1:15-3:15

The Effects of Providing Embedded Choice Making Opportunities Within and Between Daily School Routines
Lim Levan, Phyllis Darby

The Use of Picture Rehearsal to Teach Fire Safety Skills
June Groden, Amy Diller

Inclusive Early Childhood Education: Merging the Functional Curriculum Model with Developmentally Appropriate Practice for Young Children
Sara Brannan, Barbara Ludlow

Cooking with Class
Margaret Stout, Paul Stout

What Children Reveal About Their Experiences in an Inclusion Setting
Ellen Lewis

Vermont Outreach Project: Including Students with Severe Disabilities Within General Education Classrooms
Wayne Fox, Tim Fox, Kelly Leo

Advocates in Action
Deanne Gagne, Deb Griffin, Kevin McHale

This is My Life
Elizabeth J. DeBrine, Barbara Wasqatt

"I'm Pretty Happy as Far as I Know": Quality of Life as Perceived by Two Older Persons with Developmental Disabilities Living in the Community
Ann Brown-Treece, Susan Gregory

Reading and Writing Together! Literacy, Students with Significant Disabilities, and Inclusive Settings
Ayana Kee

Director of Residential Services

The ARC of Marion County, Florida seeks a Director of Residential Services. Position offers exciting opportunity to join new Executive Director and build leadership team to create continuous quality improvement culture. Ocala, Florida is a beautiful town, rated by Money magazine as the fifth best place to live in the United States. We are about one hour's drive to Orlando, Daytona Beach, and Tampa.

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TASH welcomes the newest additions to our growing list of lifetime members:

Carol Berrigan • Don Cardinal
Gunnar Dybwad • Lori Goetz
Inclusion Press • Jan Nisbet
Connie Lyle O'Brien • John O'Brien
Christine Salisbury • Ekpedeme Udofia-Ekpin

Lifetime membership entitles you to full international and chapter member benefits for your lifetime. The cost can be remitted over several monthly payments. If you are interested in becoming a lifetime member of TASH, contact Priscilla Newton at 410/828-8274, ext. 102.

• • • • • • • • • •

TASH is always appreciative of the generous contributions we receive during the year. The financial assistance of our many friends and supporters helps the organization continue to play a critical role in shaping the future for people with disabilities.

We offer our heartfelt thanks to the following individuals who contributed so generously to our work.

Christine Bevilacqua • Michael Brady
Joan Brinckerhoff • Fredda Brown
Bill Cohen • Addie Comegys
Justin Dart • June Downing
Fidelity House • Pamela Culp Hunt
H.D. (Bud) Fredericks • Deborah Gilmer
Carole Gothelf • Kensuke Kobori
Kazuko KN Nozaki • Wolfgang Plaute
Beverly Rainforth • Bonnie Starling

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by Jessica Yu

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POSITION ANNOUNCEMENT
Technical Assistance Coordinator
MARYLAND COALITION FOR INCLUSIVE EDUCATION

Join a dynamic team providing training and supports to schools as they develop inclusive services for students with disabilities in Maryland. You will collaborate with fellow coworkers, develop collaborative relationships with school-based personnel, and facilitate best practices in education for ALL students. The position involves inservice training, working with school based teams and developing strategies for systemic reform at the school based level.

REQUIREMENTS

This position requires a Master's degree in special education, general education, or a related field; a minimum of three years experience teaching students in public schools; experience in including students with disabilities in regular education classes; experience in conducting formal inservice training sessions and group presentations; experience in adapting general education curricula, and providing training to general and/or special education teachers. Waiver of any of these requirements will be considered on the basis of strengths in skill areas.

MCIE is an equal opportunity employer; we encourage all minority applicants to consider us. Position to start September, 1997.

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Carol Quirk, Professional Development Director
Maryland Coalition for Inclusive Education
7257 Parkway Drive, Suite 209
Hanover, MD 21076-1306
Phone: (410) 712-4837 FAX: (410) 712-0211

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FRIDAY, 12/12/97
8:00-10:15
2nd Annual Positive Approaches Materials Share Shop

TASH Positive Approaches Interest and Action Group is sponsoring an exhibit of materials that are used successfully to support individuals with challenging behaviors, or materials that are used to advocate for the use of positive approaches. Materials will include: workbooks, data sheets, checklists, training materials, videos, or other creative materials.

The Positive Approaches Interest and Action Group is still accepting applications to include materials in this share shop. For information please contact Denise Marshall at 410-828-8274 x103 or dmarsh@tash.org.

Tri-State Consortium on Positive Behavior Support
Jeannine Brinkley, Don Kincaid, Tim Knoster, Carol Schall

Emergency...Empowerment Through a Good Attitude Script
Maria Bove , Mary E. McNeil

The Revised Stress Survey Schedule for Persons with Autism and Developmental Disabilities
Joseph Cautela, Amy Diller, June Groden

Training and Support Materials from the RRTC on Positive Behavioral Support's State Training Team Network
Richard W. Albin

Positive Behavior Support (PBS)...Louisiana Style!
Margaret Lang, Gayle Melville, Nanette Olivier

Environmental Communication Training: A Part of An Effective Behavior Support Plan
Jeannine Brinkley, Janet Sloand-Armstrong

FRIDAY, 12/12/97
8:00-9:00

Post-Secondary Education: A Choice for Everyone
James Piet

The Patterson Advocacy Project
Selene Almazan, Pat Halle

Individuals w/Significant Disabilities at Risk for HIV Infection: Critical Issues in the Development & Implementation of Effective HIV Prevention Education (S)
Wanda J. Blanchett

Developing Quality Outcome Measures: The New Hampshire Approach (SPH)
Elliza Hobson, Valerie Bradley, Bob James

The Inclusion Support Team: Sustaining the Commitment to School-Wide Inclusion
Bobbi Schnorr, Michele Paetow

Transdisciplinary Approach to Teaching
Wynne L. Freed, Carrie ann Alto, Eileen Bayer, Nancy Fraser, Amy Gailunas, Lauralee Johnson, Darlene Jones-Inge, Arlene Lasane, Sylvia Neighbors

Including Students with Disabilities in the Regular Classroom
Daniel J. DeMarle

Implementing Inclusion in New York State's Schools: The Ideal and the Real
Parnel Wickham-Searl

Youth Menturing Youth: Case Study Reflections
Mary Ann Fitzgerald, Shawn Feltz, Gail Henning

Using Information About Behavior States in Program Design and Delivery for Individuals with the Most Significant and Multiple Disabilities (R)
Michael Arthur, Deone King

Cultivating Relationships
Jennie Todd, Jane Harlan, Peggy Holtz, Becky Troyer

Educating Children with Autism: A Decision Making Process
Larry Douglass

Oh Give Me A Home...Opening Doors to Home Ownership For Individuals with Developmental Disabilities (CL)
Russell Spearman, Debbie Berrey

Strategies for Building and Sustaining Supervisor and Paraprofessional Teams (PAR)
Anna Lou Pickett

Using Natural Supports in Inclusive Early Childhod Settings: An Emerging Promising Practice (EC)
Elizabeth Erwin

Inclusion: The Name of Our Game
Erika Shulkusky, Mary Ann Olson

Matching Students with Significant Disabilities and Classroom Teachers for Successful Inclusive Placements (R)
Lori Lillo, Maryann Demchak

8:00-8:45
Urban Strand Opening (URB)
Nancy Zollers, Alison Ford, Gwen Benson

8:10-8:45
Inclusion From the Ground Up (ER)
Arthur C. Lowitzer, Carol McMorris, Ellin Siegel-Causey

8:45-9:15
Addressing School Change Through Action Research (ER) (R)
Leslie Farlow

8:45-9:30
Lessons From a Lobster: Change is Necessary (URB)
Mary Fitzgerald

FRIDAY, 12/12/97
8:00-10:15

Personal Budgets for Employment: Choice Vouchers Managed By A State Rehab System and Advocacy Agency (EMP)
Michael Callahan, Abby Cooper

The Quality of Life of Persons Who Moved from Institutions to Oklahoma Communities (A)
Mary F. Hayden, Jerry Smith, Nancy Ward

School to Work Transition: Legal Rights to Participate in New High Quality Programs
Kathleen Boundy, Eileen Ordover

Facilitating Inclusion in Schools via Professional Development Activities for Adults
Kim Glaser, Ann Brown, Mark Canner, Magali Guenths,

Building Bridges Through Collaboration
Don Ricciato, Dan Anderson, James Cummings, James Earley, Pat Horn, Amy O'Rourke, Pam Tomassoni

Outcome-Based Person-Centered Support Strategies for People with Complex Needs
Maryam Abedi, Ayndrea Lavigna, Ellen Lewis, Cheryl Reisler-Stroll

FRIDAY, 12/12/97
9:15-10:15

Conversion: From Rhetoric to Reality (EMP)
Mary Beth Lewis, Christy Lynch, MaryJo Bernando, Kathy Patrick

Practical Strategies for Meeting the Needs of People with Autism
Jan Janzen

The Study of Roles, Training Needs, and Support Needs of Vermont's Paraeducators (PAR)
Patricia Mueller

Building a Community for ALL Children - Including Children with Severe Disabilities in Child Care (EC)
Marilyn S. Dunning, Michele T. Stuart

9:15-9:45
The Intersections of Vision and Practice: An Elementary School's Journey Toward an Inclusive Educational Community (ER)
Maureen Keyes, Nancy Yoder

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The Community's Meaning of "Inclusion": A Comparison of American Towns and Israeli Kibbutzim (IM)
Angela Novak Amado

Building Bridges into Urban Communities: Helping People with Severe Disabilities Living in Economically Distressed Neighborhoods Gain Increased Independence (EMP)
Emily B. Ellis, Debbie LaMothe

Putting It All Together (SPH)
Angela M. Hawkins, Josephine Chappell

Employer Views on Job Development Strategies for Marketing Supported Employment (EMP)
Laura Owens-Johnson

Supporting Inclusion: Facilitating Change Through A Collaborative Graduate Program (H)
Anne M. Howard, Lisa Broderick, Elaine Francis, Pamela Green, Shari Stokes

Daily Life of a Person with a Disability (CL)
Roberta Hoffman

"Ants in His Pants": Absurdities and Realities of Special Education
Michael Giangreco

Writing and Implementing Effective Sexuality Policy (S)
Patricia Carney

Including the Student with the "Invisible Disability"
Myrtle Pruden, Linda Guest

9:30-10:15
Charda Smith Consent Decree as a Result of a Law Suit Against LA Schools (URB)
Mary Falvey, Richard Villa

10:30-11:00
Urban Secondary School Struggle with Inclusion: A Look at Three Case Studies (URB)
Elizabeth Kozleski, Allison Boggs, Lydia Gutzman, Cherie Howell, Karen Jarrett, Nancy Neuhalfen, Larry Nichols, Joan Radenmacher

FRIDAY, 12/12/97
9:15-11:30

All People Have a Right to a Voice
Helen Canfield, Peggy Locke

Fresh Perspectives: Making Reports Friendly to Families & Schools
Rae Sonnenmeier, Ann Donoghue Dillon, Sandy Plocharczyk

FRIDAY, 12/12/97
10:30-11:30

Solutions to the Planning Time Dilemma
Ann Dillenbeck, Amy Kuhns Bartlinski

Pathways to Satisfaction: A U.S. Model for Inclusionary Transition
Thomas Holub

The Quality School: Choice Theory/Reality Therapy and Studnets with Significant Disabilities
David Sansone, Joseph Brescia, Joseph O'Connor, Robert Renna

Connections: Including Students with Deaf-Blindness (R)
Lori Goetz, Nora O'Farrell

Implementation and Research Issues Concerning Self-Management in the Workplace (EMP)
Keith Storey, Teresa Grossi, Carolyn Hughes

Teaching Middle School Teams Positive Behavior Supports: Moving Away From Traditional Discipline
Susan Watson, Debra Boyce, Mary Malone, Steve Parsons, Maura Reed, Kathleen Sixx

Developing Culturally Sensitive Transition Plans for Students with Significant Disabilities: A Reflective Process (IM)
Pamela Wolfe, Rosalie Boone

Meet the National Alliance of Direct Support Professionals (PAR)
Marianne Taylor, Valerie Bradley, Amy Hewitt, Julie Silver

Lesbians, Gay Men, and Bi-Sexuals with and without Disabilities: A Discussion of Solidarity and Support (S)
Bonnie Shoultz

Impacting a Lifetime Through Recreation
Kim Davis

Conducting Psychoeducational Assessment with Students Who are Deaf-Blind (R)
Harvey Mar, Nancy Sall

Antecedent Interventions for Young Children
Sharon Lohrmann-O'Rourke

Child Engagement and Co-Teaching in Inclusive Preschool Classrooms (EC)
Mary Jo Noonan

Creating, Building, and Maintaining Friendships: Collaboration of Undergraduate Students and Teachers (H)
Debra K. Lynch

New Constructions: Effective Heterogeneous Classrooms Through the Application of Constructivism (ER)
Kathy Gee, Jane Meade-Roberts, Barbara Thompson

Learning Together: Parent/Professional Training Project (SPH)
David Helm, Joanne Spencer

Redefining the Social Facilitation Role of Job Coaches at Work Sites (EMP)
Jean Gonsier-Gerdin, Hyun-Sook Park, Alex Ramos, Norma Ramos

You've Got To Keep On Keepin' On: The Challenges, Learnings, and Stories of a Support Circles Mentoring Project
Mary Jo Alimena, Kathy Lee

11:15-12:00
Is Your System Leading or Accomodating Inclusion? (URB)
Ann Halvorsen, Tom Neary, Deborah Tweithull

KATIE! Kind Appraoches to Inclusive Education: Supporting a High School Student with Autism and Challenging Behaviors
Heather Young, Kathy Foley, Barbara Gruber, Steve Lottes, David McManus, Roxanne Simmons

FRIDAY, 12/12/97
10:30-12:45

Disability Culture: Severe Disability and the End of the Modern Age
Douglas Biklen, Christopher Kliewer

FRIDAY 12/12/97
11:45-12:45

Gender, Disability, and Diversity (IM)
Rannveig Traustadottir

Revisiting Academics: Ways to Include Students with Significant Disabilities in the Core Curriculum
June Downing

Promoting Change in an Undergraduate Rehabilitative Services Program
Daniel Steere

Planned Activity Time: A Nonaversive Intervention for Supporting Family Living Through Parent Education (R)
Joanne Singer

Reforming the Way Schools and Human Service Agencies Do Business: Findings From A School-Linked Service Model (ER)
Christine Salisbury, E. Wayne Crawford, Deborah Marlowe

How to Prepare for an LRE Administrative Due Process Hearing
Patricia Cox Waldman, Selene Almazan

Teachers, Beliefs, and Strategies for Inclusion (R)
Gary Bunch, Angela Valeo

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FRIDAY SESSIONS

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Abuse and Disabilities: One Way to Respond
Fred Orelove, Anne Malatchi

Peer Support Strategies for Inclusion (R)
Craig Kennedy, Lisa Cushing

The Prader-Willi Syndrome Project for the State of New Mexico
Sandy Orne-Adams, Gail Thune

Application of FM Systems for Children Who Are Deaf-Blind
Megan Jones

Making Impact on Practice: A Personnel Preparation Partnership Model (H)
Robert Flexer, Denise Brown-Triolo, Debbie Headman, Pam Luft, Elizabeth Martonyi, Vaughn Musser, Cindy Trevino

Promoting Competitive Employment By Infusing Technology Into Vocational Rehabilitation (EMP)
Craig A. Michaels, Carol Fuhrer, Leslie J. Monsen, Meira L Orentlicher

Specialized Physical Health Care Procedures: A Survey of Service Delivery in Public Schools (SPH)
Josephine Chappell, Angela M. Hawkins

What Workers Without Disabilities Say About Their Social Relationships with Workers With Disabilities - Reciprocal Benefits of Social Inclusion (EMP)
Hyun-Sook Park, Jean Gonsier-Gerdin

Supporting People with Challenging Behavior Through Augmentative and Alternative Communication: A Research Synthesis
Pat Mirenda

Let Our Doors Be Open Wide For All People: Organizing a Religious Community To Include People With Disabilities
Lynne Sommerstein, Michelle Freid, Mark Horowitz

Exceptional Family Resources
Charlotte Johnston, Bud Cooney, Nadine Wodarczyk

Working Together: Including Pre-School Children with Special Needs (EC)
Beth Brennan, Liz Kim, Susan Porter-Beckstead, Fionna Zecca

Done "Dumbing" The Curriculum
Mary Brady, Jack McCauley

Connecting Urban Youth: Steps Toward Their Future (URB)
Rebecca Salon, Kathy Chapman, Mattie Cheek, Gail Hilliard-Nelson, Deborah Nesmith

FRIDAY, 12/12/97
11:45-2:00

Inclusion in Action: Lessons From Step by Step: Heather's Story
Jacky Comforty

FRIDAY, 12/12/97
1:00-2:00

Transition Through Technology - How to Get From Work to School
Rita Skiles, Jerry Gronewold

A Model for Proactive Professional Collaboration: Changing Beliefs and Practices in Teacher Education (H)
Mark Doyle, Joan Agosto, David Freitas, Christ Kalamatas, Elaine Meyerowitz, Pennie Olson, Valerie Owen, Daniel Snyder, Kathi Tarrant

Universal Access: A Natural Support Project with Universal Studios (EMP)
Steve Zivolich, Jan Weiner

That Kid Can't Take Shop Class- Oh Yes He Can!
Karen Frisbie, Mick Natoli, Lori Silverwatch

Invent the Future: Transition and Employment Plans Based on Gifts and Dreams
Matthew Simmons, Martha Carter, Ellen Simmons

Reflections on Preparing Teachers and Future Leaders
Carole Gothelf, Adam Fine, Jerry G. Petroff

"It's Sort of Like a Marriage": Partner Teachers and Paraeducators Working Together (PAR)
Mary Lasater

Incorporating Psychiatric Needs into the Process of Positive Behavior Change for Adults with Disabilities
Lori A. Noto, Thomas E. Milanese, Thomas Mitchell, Christopher Oliva, Elizabeth Phillips

Strategies and Tactics Used to Promote Inclusion (ER)
David Westling, Mary Frances Hanline

The Community and Beyond: New Opportunities at College
Meada Hall, Roy Lauter, Stephanie Rankin

We're NOT from the Health Department, Looking at Minimum Standard
Joni B. Martell, Paula Agins, Joshua Joyal

In-Home Behavioral Supports
Patricia Levasseur, Elaine Goudreau, Steven Shenfield

Achieving Participation and Control: Issues in Person-Centered Planning (R)
Jean Whitney-Thomas, John Butterworth, Sue Cusack, Noreen Donnelly

Life Transitions and Changes in Supports
Shelley Kinash, E. Ann Hughson

Assistive Technology: An Under-Utilized Support for Individuals with Visual Impairments in Post-Secondary Settings
Colleen Thoma, Katie Cortelyou, Susan Hamm

12:45-1:30
Academic Peer Support and Cooperative Management in Inclusive Urban Classrooms (URB)
Joseph Bernazzani Jr., Denise Link, Alex Umbria, Gerri Veitch

1:45-2:30
One School's Journey (URB)
Jane Glodoski, Jackie Brimley, Jessie Vance

FRIDAY, 12/12/97
1:00-3:15

Project ROOTS: A Grassroots Approach to Outreaching Ethnically and Linguistically Diverse Families in Western Massachusetts (IM)
Raquel Rodriguez, Angela Baez, Christine Lynch, Barbara Morrell, Juliette Hanh Nguyen

Lessons for Understanding: A Teaching Curriculum on Perspective-Taking
Terri Vandercook, Jo Montie, Pam Taylor, Lynn Walz

Being a Communication Ally: Respectful Conversation with People with Disabilities
Mayer Shevin, Nancy Kalina

Social Competence for Toddlers: A Curriculum to Enhance Peer Relations in Inclusive Settings (EC)
Mary Beth Bruder, Kerry DeBenedictis, Joan M. Nicoll

Enhancing Choice Making in Community Routines (R)
Diane Browder, Karena Cooper

Technology Enhanced Communication for Persons with Disabilities
C. David Scanlin, Dale Gardiner-Fox, Al LeFebvre, Christine Lynch, Warren Schumacher, O'Rita Swan, Deborah Wilson, Keith Woodbury

Family-School Partnerships Fostered During Transitions
Melody Nay, Harriet Cramer

Meeting Health and Educational Needs of Children and Youth in School (SPH)
Stephanie Porter, Timaree Bierle, Donna Lehr

FRIDAY, 12/12/97
2:15-3:15

A Quick Guide to Supporting Paraprofessionals (PAR)
Mary Beth Doyle

Preparing Students for the Future
Harry Fogle

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FRIDAY SESSIONS

continued from page 22

Building Inclusive Schools in Poor Urban and Rural Communities (ER)
Kim Beloin, Michael Peterson

"Who's Behind the Wheel?" The Implication of Family Driven Models in Western Mass
Doug McCallum, Joseph Castillio, Dana Dansereau, Arlene Lockenwitz, Joanne Murphy, Carmen Taylor

Effective Coping Strategies: Building the Foundation for Self-Control
Jo Lynne Mullins, Ellen Lewis

Individual Preference Advocacy Service System
Deborah Blaine, Arnie Cole, Karen McCaffery, Ryan McCaffery

Walking the Walk: Making Job Matching and Placement More Person-Centered (EMP)
Bruce M. Menchetti, Vicky Piland

Walking in Another Person's Shoes is Uncomfortable
Susan DeLuke, Martha Boose

How Do Children Make Friends: A Rural and Urban Comparison
Teri Howley, Maryann Demchak

Preparing School Children for Inclusion
Edward Cohle

Graduate Students Becoming New Faculty: Using Transition Principles to Prepare for Employment in Higher Education
Michael P. Brady, Diane Baumgart, Diane Ryndak, Fred Spooner

JASH Special Issue on Self-Determination: Meet the Authors, Know the Issues
Carolyn Hughes, Martin Agran, Linda Bambara, Fredda Brown, Michael Wehmeyer

Developing Non-Traditional Career Awareness for Students with Severe Disabilities: Using Postsecondary Education Settings as Community-Based Learning (EMP)
Melody Tankersley, Terry Jean Hudson, Lynn Koch, Jan Kreiner, Emily Parker, Debbie Webster

Involving Communities for Effective Transition Planning
Teresa Callahan

Preparing Personnel for Effective Collaborative Relationships: An Interprofessional Training Model (H)
Susan Bashinski, Winnie Dunn, Wayne Sailor, Jane Wegner

Inclusive Connections: Using Discourse-Cohorts Models to Improve Schools
Donna Wickham, Kathy Gee

— Friday Poster Sessions —

FRIDAY, 12/12/97, 9:15-11:15

Developing a Student Assistant Team: A Manual for Establishing a Peer Tutor Program
Carolyn Auld, Janice Siebenhaar, Margaret Stout

Soar to the Limits: Students With Disabilities and Their Peers Without Disabilities Build Social Relationships and Radio-Controlled Planes
Vasu Babu, Mary Stauffer

The Effects of Self-Instructional Strategy Training on Social Skills of Students with Mental Retardation in Korea
Eunhee Paik

Effective Collaboration Between Professionals and Paraprofessionals
Maryann Demchak, Carl R. Morgan

Accentuating the Positive: Using Portfolios as Authentic Measure of Learners with Significant Disabilities
Rosanne K. Silberman, Jo-Ann Wolfe

The Games We Play: The Promotion of Effective Intervention and Evaluation Practices for Children Who Are Developmentally Very Young
Mary Gatens, Carol Chinn

Developing School PATH to Inclusion and Reform
Janell Sueltz

Improving the Quality of Direct Care Staff Performance in Residential Support For Persons with Significant Disabilities
Daniel Baker

Bringing Resources, Inclusion, and Developmentally Appropriate Gains to Every Child in Mississippi
Nancy Batson, Theresa Bennett

Experts' Conclusion About Inclusionary Practices
Felix Billingsley, Lewis Jackson, Diane Ryndak

Intensive Early Intervention in Inclusive Classrooms
June Groden, Patricia Fiske, Richard Spratt

FRIDAY 12/12/97, 1:00-3:15

Supporting Teacher Assistants in Inclusive Classrooms - What We Have Learned and What We Are Still Learning
Deborah Peters Goessling

Positive Behavioral Support: Listening to the Needs of Children with Learning Disabilities
Joshua Skolnick

Inclusive Education Support Systems: Teacher and Administrator Views
Angela Valeo

Using the Wrong-Item Format to Teach Functional Rejecting
Jeff Sigafoos

The Effects of Sensory Processing on the Maladaptive Behaviors of Adults Who Have Significant Developmental Disabilities: A Pilot Study
Krysti Dezonia

A Comparative Study of the Individualized Education Plan (IEP) and the Individualized Family Service Plan (IFSP)
Byoung-In Lee, Eunhee Paik

Designing Afterschool Programs for Youth of All Abilities
Karyl Resnick, Paula Nargi

Journey's in Progress: Stories From the Community
Becky Troyer, Jane Harlan, Peggy Holtz, Kyung Kim, Jennie Todd

Shared Responsibility: Effective Job Search Strategies for Individuals and Employment Staff
Sheila Lynch Fesko

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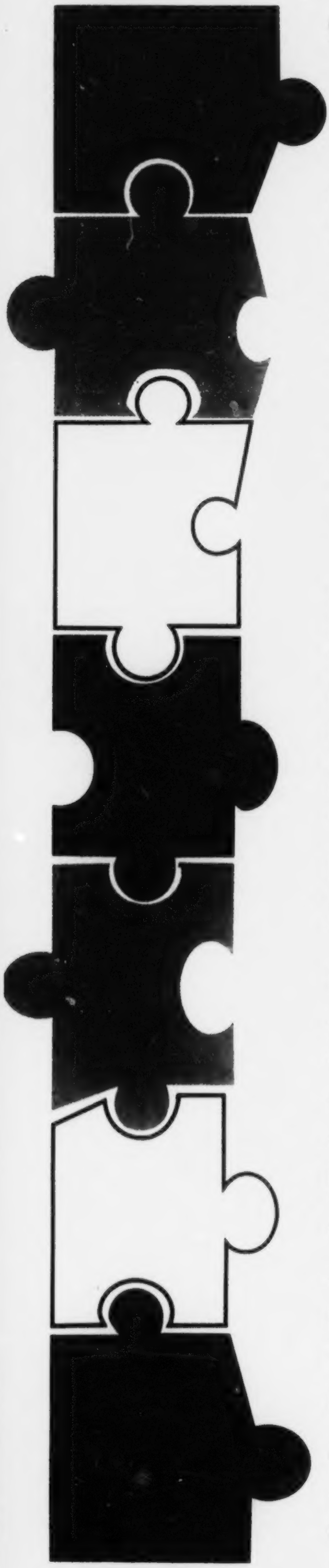


'97 Making Connections

Do you have a particular area of interest that you'd like to get together with others to talk informally about? Making Connections is a way for you to identify people at the TASH Conference who share your interests or concerns for conversation and networking. You may want to hook up with others who:

- Have children with similar disabilities to your son or daughter
- Provide progressive community living supports
- Teach children similar to those in your class
- Know about resources for students with disabilities in college settings
- Have established inclusive summer camps
- Are using facilitated communication successfully
- Want to discuss the ethics of behavioral technologies
- Share your research interests
- etc., etc.

Here's all you do. Complete and return the form below explaining your particular area of interest or the types of people you'd like to make contact with. We will publish a list of Making Connections special topics in future Newsletters and send a copy to all conference registrants. At the conference, there will be a Making Connections bulletin board with a sign-up sheet for each topic. People who would like to get together around a particular topic will sign up and leave contact information. You can then contact the people who signed up for your topic and organize an informal get-together.

Networking can be tough in a group as big and diverse as the TASH conference speakers and attendees .... Use Making Connections to simplify the processing of finding the people you need to talk to.

I want to Make Connections with people who:

____

____

____

____

Name: ______________________________

Address: ______________________________

____

Home Phone: ______________________________

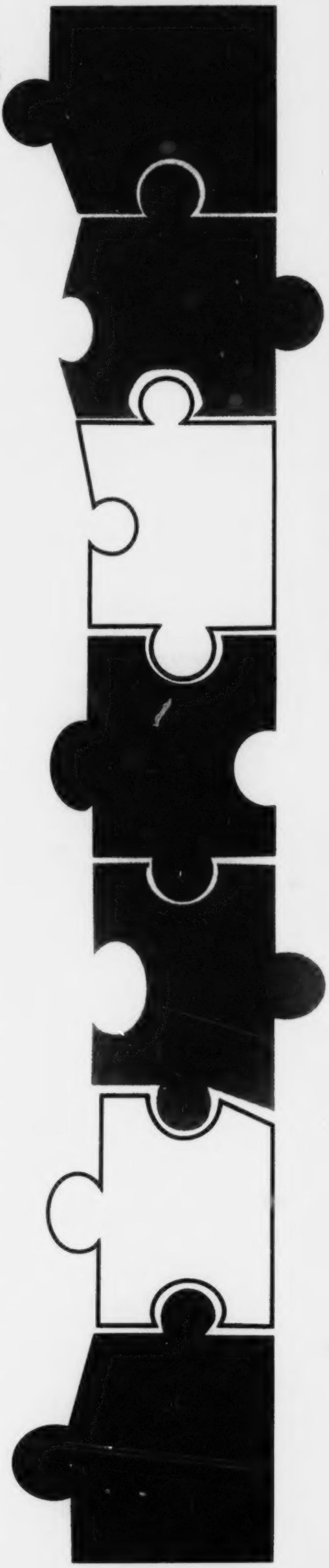
Work Phone ______________________________

Fax: ______________________________

e-mail: ______________________________

I will ____ will not ____ be staying at the Boston Sheraton. If staying elsewhere, please provide contact information while in Boston:

____



1997 TASH Conference Exhibits

Each exhibitor will receive three conference registrations, a complete booth package, TASH discounted hotel and airline rates, and the opportunity to advertise their product or services to over 2000 people from around the world.

Plan to join us in the Exhibit Hall for our Grand Opening Reception on Wednesday, December 10, 1997 from 5:00 PM to 7:00 PM.

This year the Exhibit Hall will be filled with exhibits of the products, publications and services TASH conference attendees are looking for. We welcome back many vendors familiar to our attendees and we are pleased to have many newcomers joining us in Boston. Plan to do your holiday shopping with us!

Some of the many exhibitors to be seen at the 1997 TASH conference include:

- AbleNet, Inc.; Brookline Books, Inc.
- Brooks Publishing Company
- CARF...The Rehabilitation Accreditation Commission
- Diverse City Press
- Fanlight Productions
- Inclusion International and UNESCO
- Inclusion Press
- International Down Syndrome Foundation
- Laureate Learning Systems, Inc.
- LR Consulting
- Sentient Systems Technology, Inc.
- Seven Hills Foundation
- Supported Living Technologies
- TASH Chapters & Merchandise
- The Puppet Petting Zoo
- Woodbine House
- Words+ Inc.

Added Exhibit Features to Maximize Traffic in the Exhibit Hall

- A Grand Opening Reception, Wednesday, December 10, 1996, 5:00 PM in the Exhibit Hall.
- Complimentary coffee for exhibitors in the exhibitor lounge.
- Food service in the Exhibit Hall, with ample space for attendees to browse while enjoying breakfast or lunch.
- Conference Registration and Information areas located in the Exhibit Hall.
- Direct access to the Hynes Convention Center Exhibit Hall from the Boston Sheraton.
- Entrance to the TASH Plenary Sessions through the Exhibit Hall.
- TASH Job Exchange located in the Exhibit Hall.
- The opportunity to receive a free set of mailing labels of conference attendees.
- TASH Media Festival to be held in the Exhibit Hall.

Exhibit Schedule

- Exhibit Set Up: Wednesday, December 10, 1997, 10:00 AM - 5:00 PM
- Opening Reception: Wednesday, December 10, 1997, 5:00 PM - 7:00 PM
- Exhibit Hours: Thursday, December 11, 1997, 7:30 AM - 5:00 PM Friday,
- December 12, 1997, 7:30 AM - 5:00 PM Saturday, December 13, 1997, 7:30 AM - 2:00 PM
- Exhibit Breakdown: Saturday, December 13, 1997, 2:00 PM - 8:00 PM

To obtain an application or for more information contact Rose Holsey at 800-828-8274 ext. 100, e-mail: rholsey@tash.org.

12/12/97
8:00-10:15

SPECIAL SESSION

INCLUSION ROUNDTABLE

Co-chaired by Alan Gartner and Dorothy Kerzner Lipsky, National Center on Educational Restructuring and Inclusion.

Join practitioners and parents in addressing the key issues facing inclusive education today:

- IDEA changes that affect inclusion (e.g., general education teachers at IEP meetings, placement neutral funding, statewide standards and outcome measures for all students, new per capita basis for funding states, changes in discipline standards and procedures)
- The linkage of inclusion to broad educational reform efforts
- New developments in legal actions (e.g., Boston, Los Angeles, New York)
- What are the barriers limiting the spread of inclusive education for all students.

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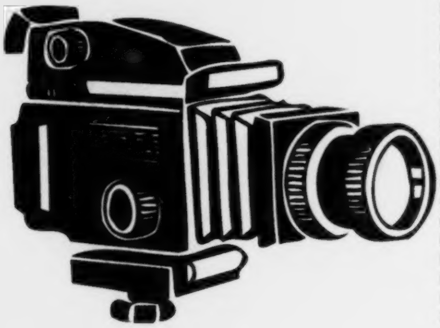

Be Seen at the TASH Media Festival!

Do you have a video that depicts the lives and experiences of people with disabilities; instructs parents and professionals who support people with disabilities; demonstrates school and community inclusion; or addresses vocational training, family issues, or any other topic related to issues for people with disabilities?

For $149 per video, you can show your video to over 2,000 conference attendees. In addition, we will print a description of your video, including your organization's name, address and telephone number, in the Conference Program.

To submit a video for the Media Festival, please contact Marcie Roth at 410-828-8274 x104 for an application.

VOLUNTEER ALERT!

With the TASH annual conference just around the corner, it's time to once again call upon the dedicated individuals who work so diligently to help us keep the conference organized and running smoothly.

YOUR SERVICES ARE URGENTLY NEEDED!

Whether you've participated as a volunteer before, or would like to do so for the first time, we welcome your assistance.

If you would like to attend the conference and save on registration fees, this is the "ideal deal" for you! Volunteers donate a minimum of 10 hours of service during the conference in exchange for complimentary registration to attend conference sessions during your non-volunteer periods.

If you are interested, please contact Priscilla Newton at
1-800-482-8274, ext. 102
and ask for a volunteer registration form.

DO YOU LIVE IN A PLACE THAT DOESN'T HAVE A CHAPTER? START ONE!

The following states/regions have chapters:

Alaska
Arizona
Arkansas
British Columbia
California
Colorado
Delaware
Florida
Georgia
Hawaii
Illinois
Indiana
Iowa
Kansas
Kentucky
Louisiana
Mid-Atlantic
Mid-Tennessee
Minnesota
Mississippi
Missouri
Nevada
New England
New Jersey
New Mexico
New York Metro
Ohio
Oklahoma
Pennsylvania
South Carolina
South Dakota
Texas
Utah
Virginia
Washington

Starting a chapter has never been easier. There has been a lot of interest expressed in seeing an international chapter established, student chapters started, and chapters set up in Michigan, North Carolina and West Virginia; and revitalizing the Oregon and Wisconsin Chapters. A special session will be held at the conference to discuss what it means to be a chapter and to review the steps for establishing one. For more information about this session or about starting a chapter in one of these or any other area, call Nancy Weiss (410) 828-8274, ext. 101; or e-mail her at nweiss@tash.org

SATURDAY, 12/13/97
8:00-9:00

What Are Life Skills? Life Skills as They Relate to Social/Emotional Strategies
Harriet Cramer, Melody Nay

The Role of the Paraprofessionals in the Inclusive Classrooms (PAR)
Randi Agetstein, Linda Smith, Jennifer Stiteler, Sheree Witt

The Role of Functional Skills and Behavioral Instructional Methods in Inclusive Education (CUR) (R)
George Singer, Felix Billingsley, Lori Goetz, Robert H. Horner, Tina Itknonen

Common Bonds: Family Linkage to Services and Success (EC)
Sally Sloop, Susan Valiquette

Health Care Ethics and Mental Retardation: Applying Internationally Recoginized Bioethical Principles to Local Ethical Dilemmas (SPH)
Betsy Johnson

Multiple Intelligence: Creating an Inclusionary Culture in Classrooms for the Deaf
Laura Davis, Linda Brion-Meisels, Judy Jacobs, Jana Trusz

If You Build It, They Will Come. If You Close It, They Can Belong (CL)
James Meehan, Gail Fanjoy

Perceptions of Music Therapists on Inclusion
Donald N. Cardinal, Lisa Jones

You Can Have Your Cake and Eat It Too — But Not All At Once
Marilyn Bown, Rich Wilson

Changing a Severe Reputation
Greta Reiman, Edward Cohle

Using a Collaborative Model for Provision of Transitional Services: Issues, Barriers and Strategies
William R. Sharpton, de Vergne Goodall

8:00-8:30
Inclusive Edcuation Statewide Systems Change Projects: Lessons Learned (ER)
Anne Smith

8:30-9:15
Data Findings From the Georgia Systems Change Project for the Inclusion of Students with Significant Disabilities (ER)
Paul Alberto, Alison Stafford

Strategies for Training Staff to Implement Community-Based Instruction Using Self Monitoring
Karena Cooper

The Importance of "We" and "All " When Providing Transition Services to Individuals Who Are Deaf-Blind
Susan K. Olson, Paige Berry

Outreaching Exemplary Transition Self-Determination Practices Through Stakeholder Involvement
Robert Baer, Lawrence Dennis, Rachel McMahan, Tom Simmons

Mediation
Nancy Algert, Linda Parrish

Systems Change: Conversion of a Rehab Center into Community-Based Support Services (EMP)
Domenico Cavaiuolo

Research on the Robert Wood Johnson Self Determination Initiative (R)
James W. Conroy

Building Inclusive Communities Through Peer Support Networks at the Secondary Level
Heather Young

SATURDAY, 12/13/97
8:00-10:15

Todos Unidos - Building and Bridging Family Strengths (IM)
Jane C. Pafford, Aureliana Alvarado, Felicita Nieves

Wake Up, It's Monday Morning!
Deborah Bain, Michael Burke, Paul Kahn, Susan Richmond, John Rubis, Cliff Sanders

Understanding Your Rights and Responsibilities Under the ADA
Kathy Gips, Myra Berloff

SATURDAY, 12/13/97
9:15-10:15

The Effects of Social Skills Training on Depression in Adults with Developmental Disabilities
Barbara Corry

Critical Issues in Curriculum for Students with Significant Disabilities (CUR) (R)
Sandra Alper, Martin Agran

Together, We Learn: Facilitating Communication and Appropriate Social Skills
Patricia Donaldson, Cathi Barr

Students Taking Education Personally (STEPs): Personal Learning Plans for All Students
Janet Lockyer, Lauren Gillis, Kelly Leo

Supporting Young Children with Disabilities in Community-Based Programs (EC)
John Filler, Janet Butz, Cynthia Lau, Catherine Lyons, Carol Matrone

Training Staff to Provide Choice Opportunities
Mary M. Salmento, Linda Bambara

Owning a Home: The Impact on the Lives of Persons with Disabilities (CL)
Nancy Robertson

Visions of "Ideal" Roles and Responsibilities for Paraeducators (PAR)
Priscilla Tucker, Bobbi Roy, Heather Schnee

Reports From the Field: Special Education and Techology
Mary Cortina

Development of the Ecocultural Interview Assessment
Jennifer J. Coots

Getting There From Here
Carol McMorris, Arthur C. Lowitzer, Ellin Siegel-Causey

Medi-Cal and Special Education Funding (M)
Lou Barber, Angela M. Hawkins

Technology's Contribution to Facilitating Inclusion in Any Classroom: Integrating Content, Computer Technology, and "Authentic" Collaboration Skills
Larry Riggs

Booker T., Birdhouses and Building Community: Exploring Non-School Instruction for ALL
Paula Kluth, Erin Diperna, Krista Hoffman

We the People Want To Work (EMP)
Kate R. Donegan, Susan E. Robinson

9:15-10:00
Systemic Change to Achieve Inclusion: The Massachusetts Inclusion Initiative (ER)
Alan Ripp, Nancy Hurley, Karen Zimbrich

SATURDAY, 12/13/97
9:15-11:30

Building Inclusive Communities Through Communication and Respect
Patti McVay, Barbara Jorgensen, Lisa McConachie, Barbara Wallace

Indicators of Performance for State Developmental Disabilities Systems
Valerie Bradley, John Ashbaugh, Susan L. Babin, Beth McArthur

The Path to Facilitated Handwriting Emanates Through Art Therapy
Belinda Todd, Michele Campbell, Alfonse Mickahail, Bethany Mickahail

SATURDAY, 12/13/97
10:30-11:30

CARF Update 1997/1998
Dale Dutton

Inclusive Education for Secondary Students with Significant Disabilities: Perspectives of Teachers and Administrators (R)
John McDonnell, Connie Mathot-Buckner, Joan Sebastian

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SATURDAY SESSIONS

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Promoting Communication Processes Involving Individuals with Severe Intellectual Disability
Nancy Butterfield, Michael Arthur, Deone King, Jeff Sigafoos

A Discussion of the Ethic of Care and Decisions that Affect Students with Disabilities
Craig Rice, James Artesani

The Decline and Fall (?) of Community-Based Instruction (CUR) (R)
Pam Hunt, Lori Goetz, John McDonnell, Mary Schuh, Carol Tashie

Expanding Community Integration and Improving the Quality and Social Life for Persons with Developmental Disabilities Living in the Community
Sandra Copman, Elizabeth Buckley

A Process, A Partnership, A Person - Deinstituionalization
Kate Blisard, Jeffrey Bruce, Bonnie Schuller, Mary Kay Weber

Including Preschoolers with Disabilities Throughout New York City (EC)
Alan Berger

Suporting AAC in Inclusive Classrooms: Collaborating with Classroom Assistants (PAR)
Michael McSheehan, Rae Sonnenmeier

New Hope For Community Recreation/ Leisure
Theresa Callahn, Becky Parker

SATURDAY, 12/13/97
10:30-12:45

The Role of Literacy in Self-Advocacy for Adults with Developmental Disabilities
Pascal Cravedi-Cheng, Rebecca Padnos, Catherine Wright, Donald Wright

The NABORS Experience: Lessons in Building Community (CL)
Judith Sandys, Beth French

Everyone Lives in a School District
Phil Drumheiser, Joe Gaskin, Andy Kach

Building Community Connections (EMP)
Cecilia Gandolfo, Melanie Jordan

Challenging Behaviors: Positive Solutions
Tim Knoster

Families of Children Assisted by Medical Technology (SPH)
John B. Susa

From Name Stamps to Laptops: Promoting Learning Through Technology
Sue Cusack

10:35-11:15
Involving Building Administrators in Planning and Implementing Effective Inclusive Education (ER)
Maryann Demchak, Carl R. Morgan

11:15-11:50
Practicing Inclusive Education: Lessons From the Lighthouse (ER)
Jerry Whitworth, Phyllis Darby

SATURDAY 12/13/97
11:45-12:45

"Pulling It All Together" (EMP)
Ron Watkins, Julie Borash, Cheryl Pennington

Residential Services..Unplugged!
Nancy Moore

A Spiritual Encounter: A Retreat Weekend for Adults
Nancy Mehlem, John L. Keck

Research on Teaching Students with Profound Multiple Disabilities (CUR) (R)
Kent R. Logan, David Gast, Heidi Jacobs

Civil Rights Litigation for Institutionalized Persons with Mental Retardation and Related Developmental Disabilities: A Review
Mary F. Hayden

Providing an Inclusive Community Through Music
Christine Routhier, Eileen Frerichs

Self-Determination for Individuals with Significant Disabilities from Early Childhood through Adolescence: Implications for Personnel Preparation
Mary Frances Hanline, Bruce M. Menchetti, Molly Sweeney, David Westling

Barriers High Schools Encounter in Sustaining Full Inclusion
Myongye Bang, Peg Lamb

"The Price of Rights"
Susan L. Babin, Linda Dvelis

Families Experiences and Perceptions of Early Childhood (EC)
Kathryn Haring, David Lovett

Helping Ourselves, Helping Others: The Creation of a Support Network for Teacher Assistants (PAR)
Deborah Peters Goessling, Joyce Almedia, Debbie Scarpelli

Facilitating Operation of a Member Run Drop-In Center: Creating New Opportunities for Empowerment with Individuals Labeled with Mental Retardation
Gail Mueller, Laurie Kimball

11:50 -12:25
Unifying Education to Improve Services for All (ER)
Doug Eicher, Tom Christie, Vicky Weseman

12:25-1:00
Administrative Challenges in Inclusive Schools (ER)
William Henderson

SATURDAY 12/13/97
11:45-2:00

Community Employment for Individuals with Significant Disabilities and Very Challenging Behaviors: A Parents "How We Do It" Workshop (EMP)
Denver Fox

"It's Never Too Late"
Ed Bielecki, Rosalyn Forsyth, Bonnie Forsyth, Peg Ingolia

SATURDAY 12/13/97
1:00-2:00

The Magic of a Multi-Age Classroom
Maria Bove

Inclusion "Failures": Lessons Learned
Colette Horn, Mary Mesick

That's What Friends Are For: Developing Peer Supports to Facilitate Inclusion
Patricia Donaldson

Assessment Through Real Life Community Experiences: Functional and Situational Assessment (EMP)
David Hoff, Karen Zimbrich

Asperger's Syndrome
June Groden, Lorraine Christie, Avis Goldenberg, Arlene Miller, Neil Miller

"Parents as Case Managers" Pilot Program
Joan Grauman, Sue Dow, Mary Beth Sanderson

"The View From the Back" Watching and Waiting to Be Part of The Crowd" (R)
Mary Fisher, Mark Larson

If We Don't Expect It, How Will We Ever Get It?: Home and School Literacy Experiences of Preschoolers With and Without Disabilities (EC)
Pat Mirenda , Chrisitine Marvin

Medicine, Ethics, and the Third Reich: Historical and Contemporary Issues
John Michalczyk, Deborah Peters Goessling

Project NEXUS: Linking Education for ALL Students
Barbara Allgood-Hill, Sandra Frain

Option Communication
Masoud Moazami

New This Year! *Saturday Special*, A Full Day Conference within the Conference

"Teaching Students with Significant/Multiple Disabilities in General Education Settings"

Saturday, December 13, 1997, 8:30 - 3:00

This exciting one day workshop will be available at no extra charge for those who have registered to attend the full conference and for people who prefer to attend only on this day (see conference registration form for rates.)

The conference is targeted for teams, administrators, educators, paraeducators, parents, and related service personnel. After a general opening session, there will be 5 concurrent sessions in the morning and afternoon from which to choose!

Opening Session Keynote: Lou Brown (University of Wisconsin)

CONFERENCE OBJECTIVES:

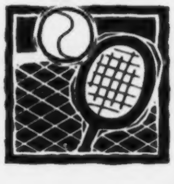
Participants will:

- obtain cutting-edge information on the key elements for success when including students with significant and multiple disabilities in general education settings
- benefit from a "practitioner to practitioner" focus
- participate in discussion of successful strategies for inclusion
- learn about regional inclusion exemplars
- create regional networking opportunities
- obtain resources and materials on a wide variety of subjects including team models, systems change, curriculum, administrative issues, inclusion models, parent perspectives and empowerment, and much more!

Call the TASH Central Office, 1-800-482-8274 for more detailed information about this exciting day!

This conference is being coordinated by Donna Lehr (Boston University), Sue Gurry and Anne Larkin (Lesley College), Nancy Zollers (Boston College), Ann Howard (Fitchburg State College), Karen Lifter (Northeastern University), and Liz Fleming and Bruce Gordon (Westfield State College).

The Leisure and Recreation Interest and Action Group will be organizing an Integrated Sports Roundtable discussion at the conference. One of the goals of this session will be to take a more active role in planning opportunities that are inclusive, and holding discussions with Special Olympics, Inc. If you are interested in participating in such a forum, please call Cynthia Burkhour at 616-669-9109 or send her an email at accessrecreationgroup@juno.com



MANAGER
of
SUPPORTED LIVING SERVICES

Manager of supported living services for adults with developmental disabilities in So. California-Los Angeles area.

Masters degree in Psychology or related field and at least two years supervisory experience in the field is mandatory. Salary commensurate with experience.

Mail resume with salary history
to IABA, Attn: Maryam Abedi,
5777 W. Century Blvd., #675,
Los Angeles, CA 90045.

WE THE PEOPLE
ALL THE PEOPLE!
TASH CONFERENCE
BOSTON 1997

It's Time for the TASH Job Fair!

This year's exciting TASH annual conference in Boston is expected to attract over 2,000 of the most progressive employers and professionals in the disability community from across the country and around the world!

Are you looking to fill positions within your agency? Are you considering a job change?

■

The TASH Job Fair will provide opportunities for job seekers to review a broad range of available jobs, all in one place, all in a few hours. The Job Fair will allow employers to meet qualified applicants in behavioral support, community living, early childhood services, education, family support, personnel preparation, recreation/leisure, related services, special health care needs, and supported employment. Employers can even schedule time to use conference-style interview space in private and at no cost.

■

The TASH Job Fair offers three ways for employers to recruit and review applicants:

- Low cost classified ads in the conference program;
- Exhibit space in a special Job Fair section of the Exhibit Hall;
- Private interviewing space to conduct group or individual preliminary interviews with applicants.

Applicants can bring copies of their resumes to distribute to employers offering positions of interest or can submit their resume in advance with a letter describing the type of position they seek. **THERE IS NO FEE FOR APPLICANTS TO PARTICIPATE IN THE JOB FAIR!** TASH will duplicate the resumes and letters and provide them in advance to all appropriate employers participating in the Job Fair. All resume submissions will be kept confidential. Employers can then contact potential applicants prior to the conference to establish interest and schedule interviews.

We understand that job openings are not predictable. On-site employer registration will be available to get the word out on last minute job openings, if space is available.

FEES ARE AS FOLLOWS:

Exhibit space at the four hour Job Fair exhibit	No Charge
Space on the volunteer-staffed display table	$15
Display ads (to appear in the conference supplement):	
1/4 Page	$25
1/2 Page	$35
Full Page	$45
Private, conference-style interview space	No Charge

(available anytime during the conference)

To receive more information on the TASH Job Fair or to register to participate, please call Priscilla Newton at (410) 828-8274, ext. 102 or e-mail pnewton@tash.org.

THIS YEAR'S JOB FAIR WILL BE HELD IN THE EXHIBIT HALL ON FRIDAY, DECEMBER 12, 1997 FROM 8:30 A.M. TO 12:30 P.M.

New York Metro TASH Conference

"Putting Children First"

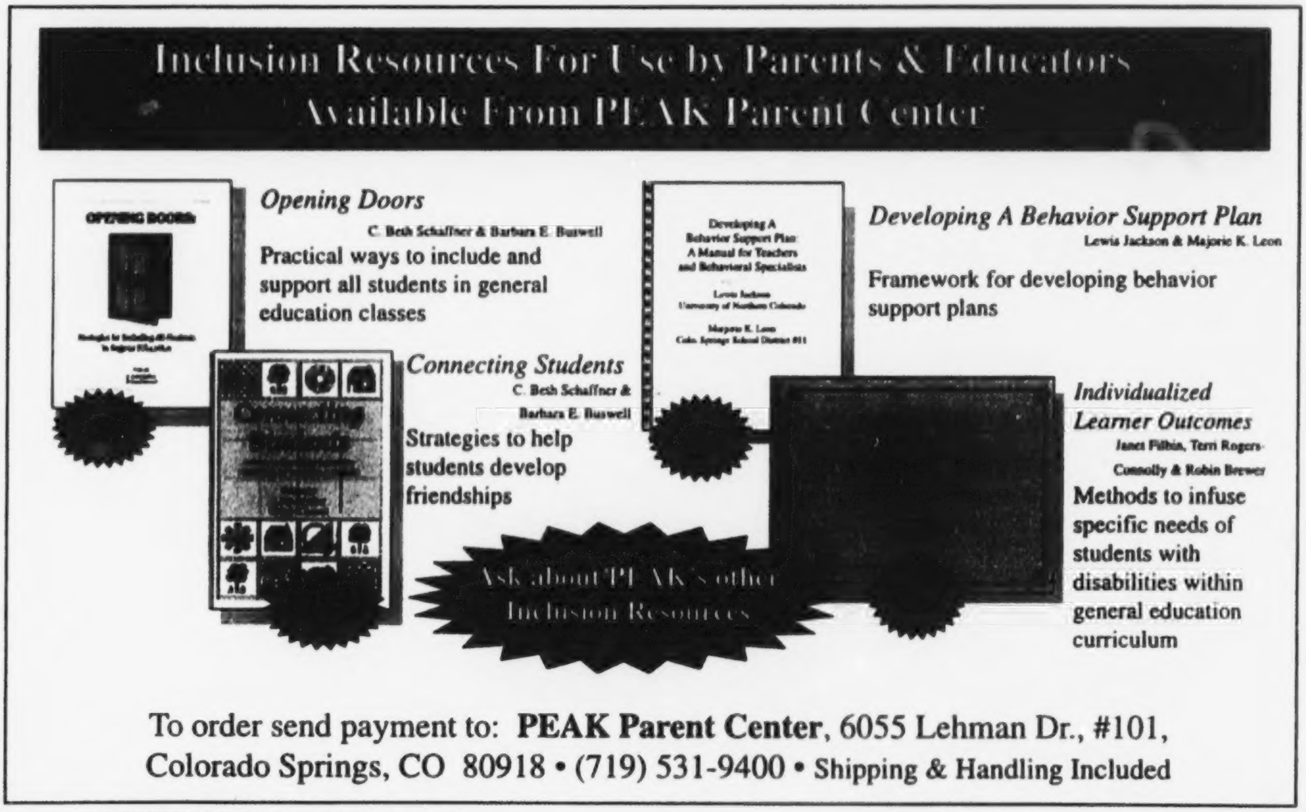
Friday, October 17, 1997
Queens College

Keynotes:
Congressman Major Owens
Representative from Children's Defense Fund
(Invited)

This conference, designed as a follow-up to the "Stand for Children" march sponsored by the Children's Defense Fund, will help to empower people focused on many of the issues affecting children today. Sessions include AIDS and children, poverty, homophobia, the militarization of schools, cooperative learning, challenging behaviors, parenting, inclusion, Head Start, multiple intelligences, and facilitated communication. For more information contact: Christine Mack, President NY Metro TASH, 718-527-5220.

Club TASH
TASH CHILD CARE

Child care is available while you're attending the TASH 1997 conference in Boston. The child care services will be professionally operated. A range of fun activities are planned for children aged six months through thirteen years old. Child care will be provided during all hours that sessions are scheduled. The charge for child care is $2 per hour, per child. To take advantage of this service you must complete the Child Care Registration form on the next page and submit it so that it is received at the Baltimore TASH office no later than December 1, 1997.


Inclusion Resources For Use by Parents & Educators
Available From PEAK Parent Center

Opening Doors
C. Beth Schaffner & Barbara E. Buswell
Practical ways to include and support all students in general education classes

Developing A Behavior Support Plan
Lewis Jackson & Majorie K. Leon
Framework for developing behavior support plans

Connecting Students
C. Beth Schaffner & Barbara E. Buswell
Strategies to help students develop friendships

Individualized Learner Outcomes
Janet Filbin, Terri Rogers-Connolly & Robin Brewer
Methods to infuse specific needs of students with disabilities within general education curriculum

Ask about PEAK's other Inclusion Resources

To order send payment to: **PEAK Parent Center**, 6055 Lehman Dr., #101,
Colorado Springs, CO 80918 • (719) 531-9400 • Shipping & Handling Included

TASH Child Care Registration Form

Please fill out this form and return to TASH at the address listed below. *MAKE CHECKS PAYABLE TO TASH.* A confirmation letter with release forms and a history/information form will be sent to you once payment is received. Please indicate the age each child will be on December 1, 1997.

CHILD'S NAME__________________________ **AGE:**_____ **SEX:**____ **BIRTHDATE:**____________
CHILD'S NAME__________________________ **AGE:**_____ **SEX:**____ **BIRTHDATE:**____________
CHILD'S NAME__________________________ **AGE:**_____ **SEX:**____ **BIRTHDATE:**____________

Rates are $2.00 per hour per child with a consecutive three hour minimum period required.

Day	Hours of Operation	Specific Hours of Care Requested	Number of Children	TOTAL Per Day
Wednesday 12/10/97	8:00-4:30			$
Thursday 12/11/97	7:45-5:45			$
Friday 12/12/97	7:45-5:45			$
Saturday 12/13/97	7:45-2:30			$
		Non-Refundable Reg. Fee $5.00		$
		GRAND TOTAL		$

Payment: ****Check***____ ***Visa***____ ***Mastercard***____ ***Discover***____
Card#____***Exp. Date***_______________

The Child(ren) named above will be released ONLY to the person(s) signing this application and the following additional person(s):

Father/Guardian Full Name:____________________________ **Signature:**_____________________
Mother/Guardian Full Name:____________________________ **Signature:**_____________________
Address:_______________________ **City:**_________________ **State:**__________ **Zip:**__________
Home Phone#:__________________________ **Daytime Phone#:**________________________________

Mail this completed Registration Form and FULL PAYMENT payable in U.S. Funds NO LATER THAN 12/1/97 to TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204.

For Office Use Only
Amt. Recvd._____ Amt. Due_____ On Timeline______ In Comp.______

TASH Conference Registration Form

"We the People, *ALL* the People"

Sheraton Boston, December 10 - 13, 1997

Mail form to: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204-5201
Fax form to: TASH, (410) 828-6706. TDD (410) 828-1306 • Questions? Call 1-800-482-TASH
The registration application can also be found at http://www.tash.org

Registration Discounts

10% Earlybird Discount for Registrations postmarked by September 15, 1997.

10% Discount for groups of 5 or more registering together (must be mailed and received in the same envelope).

50% discount off the rate that applies (for each person) for a regular education teacher registering with a special education teacher, a paraprofessional, or related services personnel; or for any support staff person registering with a self-advocate (must be mailed and received in the same envelope).

***Only one discount in addition to the earlybird discount is allowed.**

You may use this form to register for the conference only, to register for the conference and become a TASH Member or renew your membership at the same time, or to become a member only

Please Print

Last Name ______________________ First Name ______________________

Preferred Badge Name ______________________

Agency/School/University ______________________

Mailing Address ______________________

City/State/Province ______________ Zip/Postal Code __________ Country ______________

Billing Address ______________________

City/State/Province ______________ Zip/Postal Code __________ Country ______________

Daytime Telephone ______________ FAX ______________

E-mail ______________________

Please enter the code off the brochure mailing label (if applicable) ________

Please Circle the Appropriate Number(s)

1 University/College Educator
2 Special Education Teacher
3 Professional Development
4 College Student
5 OT/PT
6 Legal Advocate
7 Regular Education Teacher
8 Administrator
9 Social Worker
10 Speech/Language Pathologist
11 Family Member/Parent
12 Self-Advocate
13 Support Services Provider
14 Government Personnel
15 Supported Employment
16 Psychologist
17 Early Childhood
18 Other

Please fill out this section only if you are registering for the conference:

TASH Membership: ☐ Individual ☐ Agency Membership #______________

(please note: up to three persons can register at the membership rate using an agency membership)

Student ID# (if applicable) ______________________

☐ I am becoming a member now
☐ I am renewing my membership now
☐ Please check here if you are a TASH Lifetime Member with Conference Privileges
☐ Please check here if the address above is a new address

Optional Service Information Requested (please request by November 1)

☐ Accessibility Details
☐ Sign Language Interpretor
☐ CEU Credits
☐ Child Care/Youth Activities (Note: you must fill out an application in advance to register. Space is limited)
☐ Roommate Referral Program
List any accommodation needs ______________________

To Become a TASH Member or renew your Membership NOW. . .

You may also use this form to become a member at the same time you register for the TASH conference! This allows you to register for the conference at the reduced TASH member rate (see other side for member registration rates) or, *use this form to join as a member without registering for the conference.*

Membership rates are listed below. Determine the appropriate membership category, be sure to fill in the applicable rate on the reverse side of this form when entering payment information, and include payment at the time you submit your conference registration payment.

General International Membership (individuals)	$85.00
Agency/Business/University International Membership	$190.00
Self-Advocate, Parent, Full-Time Student, Direct Support Worker, Paraprofessional, Personal Attendant, International Membership	$45.00
Family International Membership (2 people)	$130.00
Lifetime International Membership	$1,000.00

(Add $15.00 to memberships outside of the U.S. and Canada to cover additional postage costs)

Fill in appropriate membership rate on Line 4 on reverse side of this form.

1997 TASH CONFERENCE - "WE THE PEOPLE, ALL THE PEOPLE" - DECEMBER 10-13

Registration Rates 1997 Conference	Current or Joining International Member	Non-Member	Please Enter Applicable Cost
General	$169	$289	
Student/Paraprofessional/Parent (Professional)	$135	$229	
Family (2 People)	$204	$420	
Self Advocate/Parent (non-professional)	$ 29	$ 39	
One Day Only ☐ Thurs or ☐ Fri	$ 99	$129	
Saturday Only Special	$ 70	$ 85	

1 Cost for Conference Registration from above .... 1. ________

- Less 10% Discount for Earlybird Registrations (must be postmarked by Sept. 15th) .... ________
- Less 10% for Group Discount or 50% for other discounts .... ________
- Please enter if applicable, see other side for details **(only one discount in addition to earlybird discount is allowed)**

Add discounts .... ________

2 Total Conference Registration Rate (Subtract discounts from line 1) .... 2. ________

Rates to add a Pre-conference Full Day TASH Tech Workshop (see descriptions, pgs. 8-9)

TASH Members	$65.00	NOTE: There is no charge for the Chapter Leadership Tash Tech.
Non-Members	$75.00	
Self advocate/Parent	$40.00	

1st Choice Tech # ______
2nd Choice Tech # ______

3 Add Cost of TASH Tech if applicable .... 3. ________

4 TASH Membership Dues Enclosed (If renewing or joining with this application, add applicable rate from other side) ..... 4. ________

5 To Also Join Your State Chapter Add $15.00 .... 5. ________
(only applicable if joining or renewing TASH international membership now)

6 Yes, I will donate $5.00 to support a self-advocate to attend the conference .... 6. ________

Grand Total Enclosed (add applicable costs for lines 2-6) ________

Payment Terms

Registration will not be accepted without payment by check, official purchase order, or credit card authorization. Please note that payment must be in U.S. Funds only. A $25.00 processing fee will be deducted from cancellations received before November 15, 1997, and added to purchase orders not paid within 30 days after the conference. No refunds will be given for cancellations after November 15, 1997. After that date, registrations will be on-site only and a $35.00 processing fee will be added to all registrations. A $15.00 fee for returned checks or unauthorized charges will be assessed.

Check enclosed Purchase Order/State Voucher No. ________________

Visa Mastercard Discover Card Number ________________ Exp Date ________

Signature ________________

Innovations

Invitation for Submissions

ABOUT THE SERIES

Innovations is a publication of the American Association on Mental Retardation that brings research to practice. Designed for busy practitioners, Innovations translates research findings into clear, usable ideas. Each issue is devoted to one topic. Recent issues have included:

Opportunities for Daily Choice Making	by Bambara & Koger
Teaching Practical communication Skills	by Dyer & Luce
Community-Based Instructional Support	by Test & Spooner
Teaching Buddy Skills	by English, Shafer, Goldstein, & Kaczmarek

CALL FOR CONTRIBUTORS

Submissions of proposals for the 1998 series are invited. Potential contributors are requested to prepare a 2-3 page proposal including a description of the topic and its importance, an outline of the content and references. If a proposal is accepted, a full manuscript will be invited for review. The deadline for the next round of review is October 1, 1997. Mail 8 copies of the proposal to Diane Browder, Editor of Innovations, Lehigh University, 319A Iacocca Hall College of Education, Bethlehem, PA 18015.

1997 Reviewers

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Deborah Gilmer

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on language "that emphasizes the humanity of people with handicaps." Terms such as "the autistic," "the retarded," and "the severely handicapped" refer to characteristics, not individuals. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Executive Board
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Carmen Ramirez
Linda Rammler

MEMBERSHIP INFORMATION

Referred by: ______

Name: ______

Address: ______

City/State/Zip: ______

Telephone: ( ) ______ Fax: ( ) ______

Please Check Appropriate Categories
(not more than three):
( ) Administrator
( ) Adult Service Provider
( ) Case Manager
( ) Day Personnel
( ) Early Childhood Services
( ) Educator (University/College)
( ) Early Intervention Specialist
( ) Friend
( ) Gov. Personnel (Federal, State, Local)
( ) Higher Education
( ) Human Services Provider
( ) Interested Individual/Advocate
( ) Legal Administrator
( ) Occupational/Physical Therapist
( ) Paraprofessional/Direct Care
( ) Parent/Family Member
( ) Primary Care Provider
( ) Personal Assistant
( ) Professional Advocate
( ) Psychologist
( ) Regular Education
( ) Residential Services
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Student (College/University)
( ) Support or Related Services
( ) Supported Employment Personnel
( ) Teacher (Direct Service)
( ) Teacher Trainer
( ) Vocational Services
( ) Other

General Membership (individual)	$85.
Agency/business/university/ college/library/school (allows three conference attendees)	$190.
Self Advocate, Parent, Full Time Student, Direct Careworker/Paraprofessional/ Personal Attendant (for whom payment of full fee would present a hardship)	$45.
Family (group rate)	$130.
Lifetime Member	$1000.

All dues are $15 higher for members outside the U.S. & Canada. Funds must be submitted in U.S. Dollars.

If you would like to charge your membership, please fill in the necessary information:
( ) Mastercard ( ) Visa ( ) Discover

Card Number ______

Expiration Date ______

Signature ______

( ) I would like to arrange to spread my payments out.
Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

How did you learn of TASH: ______

What, in particular, inspired you to join: ______

What other disability organization do you belong to: ______

If you are applying for a student membership, please provide the following information:

Department ______

College/University ______

Student I.D. Number ______

Anticipated year of completion ______

( ) Please check here if you would like us to send information about your local TASH Chapter.

Please make check payable to: TASH
Address: 29 W. Susquehanna Avenue
Suite 210
Baltimore, MD 21204
Telephone: 410/828-8274 Fax: 410/828-6706

MOVING?
Please notify TASH of your new address.

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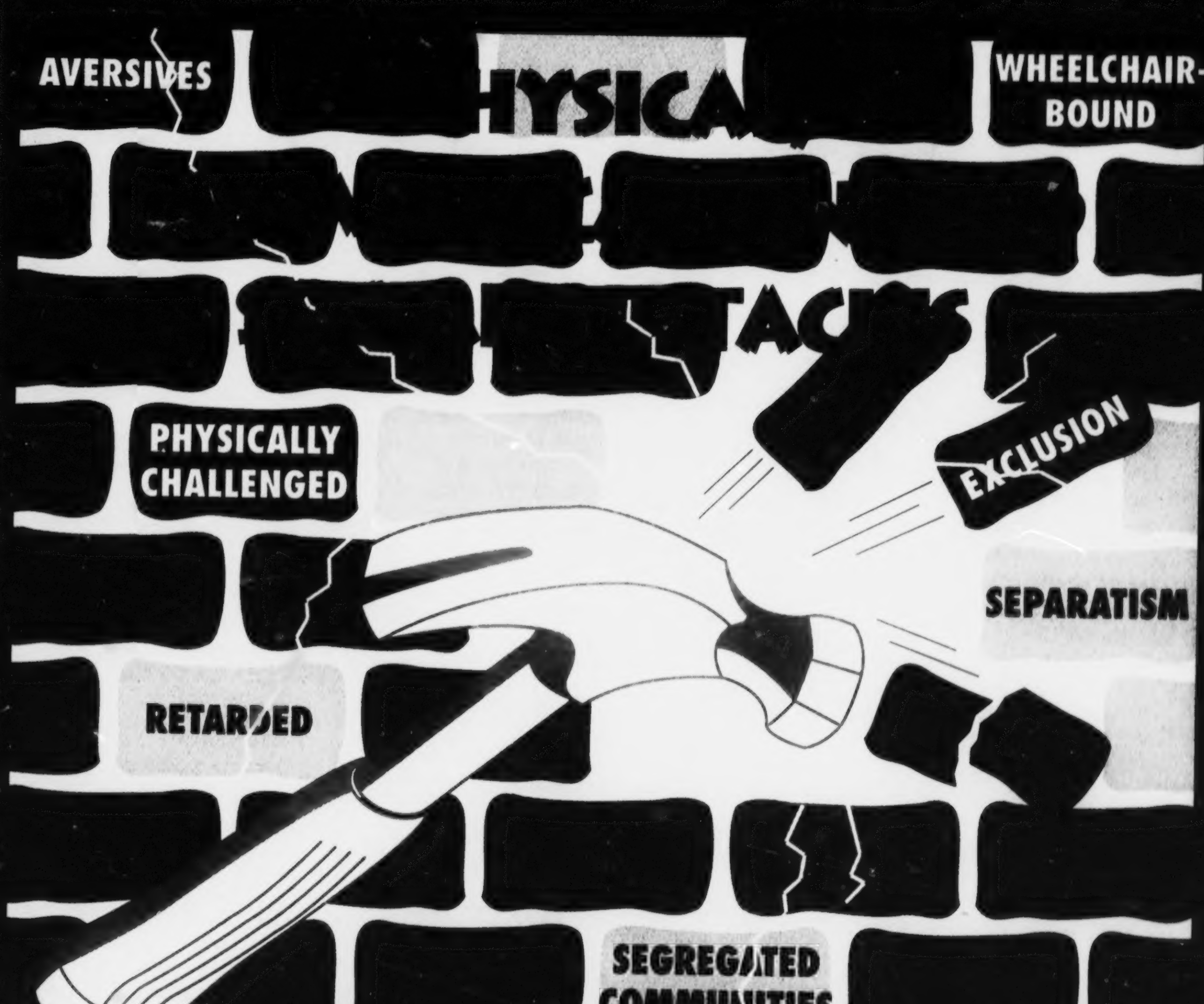
Phone: 410/828-8274, FAX: 410/828-6706, TDD: 410/828-1306

Address Correction Requested

Newsletter

BREAKING DOWN



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WE THE PEOPLE
ALL THE PEOPLE!
TASH CONFERENCE
BOSTON 1997

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Full Page	$45
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THIS YEAR'S JOB FAIR WILL BE HELD IN THE EXHIBIT HALL ON FRIDAY, DECEMBER 12, 1997 FROM 8:30 A.M. TO 12:30 P.M.

BEST COPY AVAILABLE

SHAFIK ASANTE

1949-1997

It is with deep sadness that we announce that our friend, colleague, and co-learner -- indeed one of our leaders -- Shafik Asante, passed away on Friday, Sept. 5, 1997.

Shafik's family said that the message he wanted to relay to people is that he lived a very full life of commitment and principle despite waging a 20 year battle against cancer. On Sept. 5, 1997 he began a new chapter of his life, which is how he saw death. In a letter that he left for his family he stated the following:

"Let it be known that I have lived very well and therefore I welcome my death with open arms. The purpose of life is to live . . . I have done that. Now let me be!"

Services for Shafik were held on Monday September 8. He was then taken to Harpers Ferry, West Virginia. A memorial service was held on Sunday, September 28 at the American Friends Center in Philadelphia, PA.

Shafik Asante was born and raised in Philadelphia. As the founder of the New African Voices Alliance, Shafik brought together African American community organizers to fight against the many injustices prevalent in the African American community. As director of COMMUNITY AWARENESS NETWORK, Shafik worked with diverse cultures, uniting them in struggles for better community services. Shafik received numerous awards for community organizing and was recognized as an outstanding community leader. Shafik gained national and international recognition as a writer and presenter. He was an affiliate of the California-based Tools for Change and the Canadian-based Center for Integrated Education and Inclusion.

Marsha Forest, Jack Pearpoint, and Judith Snow will coordinate a memorial service to Shafik at the 1997 TASH Annual Conference. They had this to say in remembrance of Shafik:

"For those of us privileged to have worked with Shafik, his wisdom and inspiration will carry on. His 'leading ideas' will continue to lead. Who can forget 'airplanism,' 'colorism,' 'unlearning and relearning,' 'alliance building,' 'quilted circles,' 'villaging,' and his enduring capacity to help each and all of us to learn to just live together."

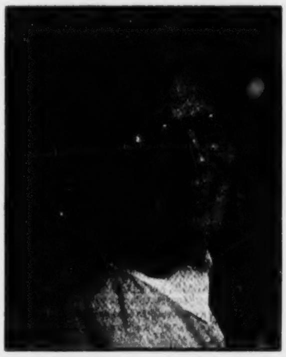
Donations may be made to: Community Awareness Network, 403 North 54th St., Philadelphia, PA 19139.

■

A quote from Shafik about a friend:

"Our death is but a small 'event' which occurs within the 'process' of our lives. It is but one little chapter in our book of life. Death does not end the book, only that chapter. Let us remember . . . and honor . . . with our practice of ending all 'isms' that separate us one from another. All seeds must die in order to develop. [People] will continue to develop as long as we continue to remember [them] in our own work and in our own chapters. As long as one is remembered, one lives!" — *Shafik Asante*

■



EVAN J. KEMP, JR.

1937-1997

The disability community lost one of its stalwart rights activists on August 12, 1997. Evan Kemp was a visible and powerful disability advocate and activist, well-known and respected in Washington and in the disability community. Appointed to the Equal Employment Opportunity Commission during the Reagan Administration, Evan was appointed chair of the Commission during the Bush Administration.

A graduate of the University of Virginia Law School, Evan came to the EEOC after spending eight years as executive director of the Ralph Nader-sponsored Disability Rights Center. After leaving the EEOC in 1993, Evan started his own company, Evan Kemp & Associates, which provides state-of-the-art equipment, products, and services designed to enhance the quality of life for people with disabilities.

Longtime TASH member Justin Dart had this to say about Evan:

"It was my privilege to work with him over the years in the struggle for justice - to speak from the same podium, to roll in the same marches, to celebrate at the same table. We fought together for ADA, accessible buses, and personal care assistance for all, and against pity-based telethons.

ADA would not have passed without him. Most recently, we issued a joint statement in opposition to the assisted suicide movement, and spoke together at the NOT DEAD YET rally in front of the Supreme Court . . . Evan Kemp was a great American. With the constant support of magnificent Janine Bertram [his wife and partner], he lived and died as a patriot, fighting for democracy right up to the last day."

TASH extends its deepest sympathy to the family, friends, and associates of Evan Kemp, Jr. He will be missed.

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TASH (The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services

EDITOR'S NOTES

This month's *Newsletter* opens with the sad news of the passing of two of the disability community's most respected activists, Shafik Asante and Evan Kemp. It is fitting that several of the articles in this *Newsletter* weave a common theme around knocking down barriers that prevent equity and quality of life, as both of these advocates were known and respected for their many years of work in the social justice movement.

In this issue you'll find Cindy Burkhour's description of simple yet effective ideas to integrate children with and without disabilities in youth sports activities (page 6). Developing creative ways of using inclusive "linking" and "thinking" to build community within schools is explored by John O'Brien and Connie Lyle O'Brien (page 8), while Denise Marshall describes the information shared and the topics of concern that were voiced during the recently-concluded Complexities of Community Building Workshop (page 24).

Beginning on page 14, Jack Pearpoint and Marsha Forest offer another in a series of useful, creative problem solving tools. Shawn Kelly reminds us there is still a long way to go in eliminating barriers to social integration as he shares the hurdles he encountered in trying to integrate into the gay community (page 17). TASH members Fredda Brown, Fredda Rosen, and Lisa Pitz brought to the attention of the New York Times their personal story of working for over two years to move James Velez from the infamous JRC/BRI into his own apartment. Excerpts from the Times' multi-part series on James appear on page 27.

And don't forget to send in your registration form for this year's annual conference in Boston - it'll be here before you know it!

— Priscilla Newton, Editor

WHOM DO I CONTACT??

- **For issues of policy, chapter or committee support or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on the conference, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about conference registration or exhibiting call:** Rose Holsey, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on government affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:mroth@tash.org
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- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230, e-mail: lgoetz@sfsu.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

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FROM THE EXECUTIVE DIRECTOR
BY NANCY WEISS

There are two major movements afoot that may significantly affect the way that disability supports are made available to people with disabilities in the future. Adults with significant disabilities often are treated as commodities...they are selected, placed and moved as suits the will of the system. In most states, when an opening ("bed," "slot," or "placement") becomes available at a community residence, the state assigns an individual from the state-operated facility to fill that vacancy. The individual is given no say about where or with whom he/she will live or which agency or particular staff will provide support.

Similarly, in most states when new monies become available to move people from state facilities to the community, states "put people out to bid." The process is more subtle than slave or cattle auctions at which an auctioneer describes the attributes of the offered "property" and ownership is passed to the highest bidder, but the implications and results are much the same. States make available a list of people who are deemed ready to move from the institution. Private agencies that provide residential and/or day services review those people's records, talk to institution staff, and meet briefly with the individual and sometimes his/her family members. The agencies then develop plans and budgets based on the amount they think will be required to adequately serve the individual and submit these as bids to the state. The state selects the provider based on the quality of the plan and the associated costs. Again, any preference on the part of the individual and his/her family is at best secondary to the political process, if it is even sought or considered at all.

Parents, especially older parents, who have had their adult sons or daughters on waiting lists for years are expected to be appreciative that any community services are being offered at all. And often, this is the case as parents realize that if they reject offers of service from a particular agency, another offer may be long in coming. People with the disabilities and their family members are reluctant to question the quality of supports being offered for fear the supports will be withdrawn entirely.

The first of the new efforts that has the capacity to totally re-invent this approach to service delivery is the brainchild of Tom Nerney, a long-time TASH member and leader. Tom and project Co-Director Donald Shumway have received funds from the Robert Wood Johnson Foundation to provide seed money for pilot self-determination projects in 28 states. Each of these states is experimenting with ways to reverse the traditional assignment of power and build a foundation for people with disabilities and their family members to design and determine their own futures. Essential to this paradigm shift is that the money for services and supports under these emerging models is held and controlled by the individual with disabilities.

It has been in vogue for some time to refer to people with disabilities as "consumers," but the term has until now had an empty ring. One self-advocate, in explaining his dislike for the term, said that he has never felt like a consumer of services, rather, he said, "I feel that I have been consumed by them." People with disabilities will be consumers only when they are able to survey the range of support options, select those that suit them and, if dissatisfied, take their business elsewhere. The Robert Wood Johnson multi-state initiative gives people this option on a broad scale for the first time in history. The November/December issue of the *Newsletter* will be devoted to the Robert Wood Johnson Self-Determination Initiative and will highlight the creative approaches state projects across the nation are taking to achieve true consumerism.

The second major movement that has the potential to significantly change the face of disability supports is a new bill that was drafted by Mike Auberger, Bob Kafka and other ADAPT leaders over two years ago. The bill was originally called CASA (Community Attendant Services Act) but it is now being referred to as MI CASA (Spanish for "my home") and stands for the Medicaid Community Attendant Services Act. After months of hard work on the part of ADAPT and other disability advocates, the bill was finally introduced in the House in June by

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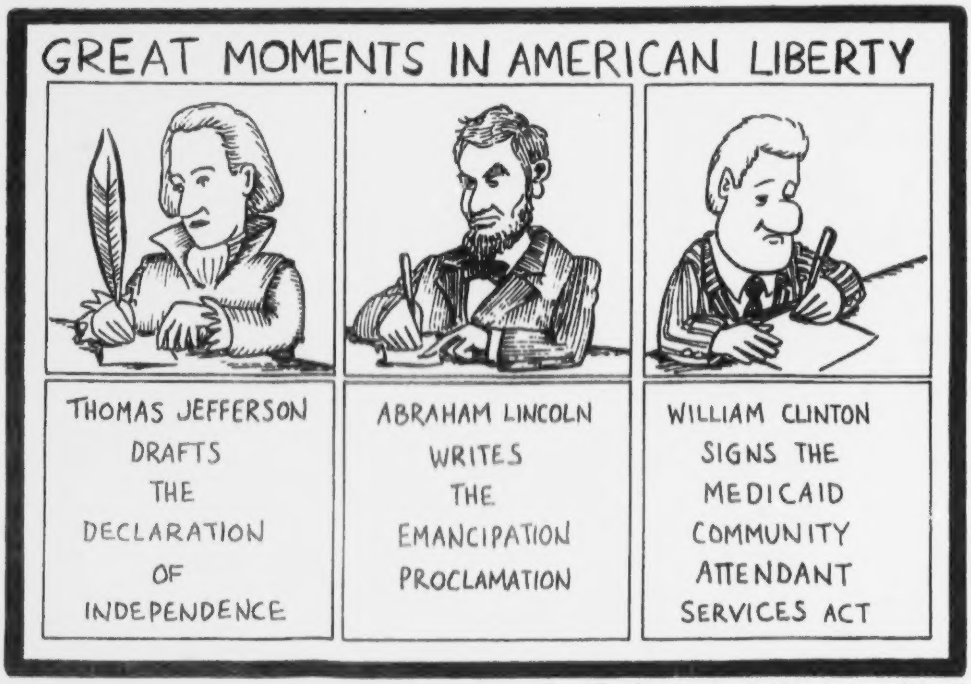
GREAT MOMENTS IN AMERICAN LIBERTY
THOMAS JEFFERSON DRAFTS THE DECLARATION OF INDEPENDENCE
ABRAHAM LINCOLN WRITES THE EMANCIPATION PROCLAMATION
WILLIAM CLINTON SIGNS THE MEDICAID COMMUNITY ATTENDANT SERVICES ACT

Scott Chambers (reprinted with permission of Mouth)

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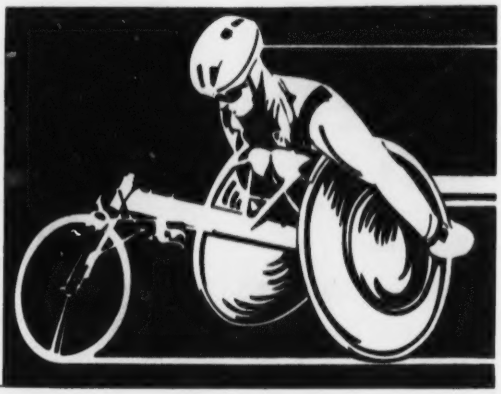
CHILDREN WITH DISABILITIES IN YOUTH SPORTS



BY CYNTHIA BURKHOUR

Can children with disabilities play successfully in youth sports programs? Absolutely! ALL kids have different levels of ability. ALL kids have unique skills that coaches blend to create well balanced teams. ALL children can and do benefit from the experience of being a part of a team. Children who have disabilities also have unique skills, different levels of abilities and benefit the same as other kids from the youth sports experience. Kids with disabilities are "children first and foremost," with the same dreams and aspirations as other kids. The only difference is that they happen to have a condition which may affect some of their abilities and skills.

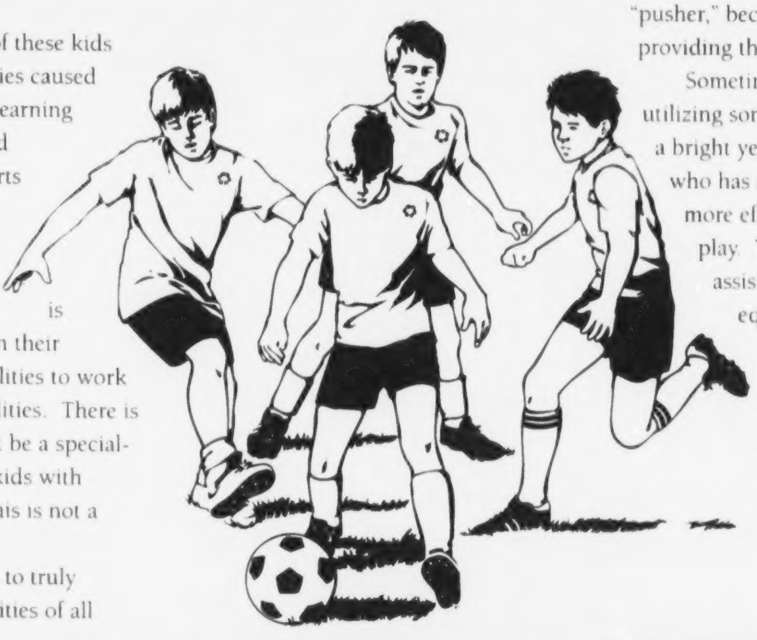
Unfortunately, some of these kids who have "different" abilities caused by a physical, sensory, or learning disability have been denied participation in youth sports programs with their peers who do not have disabilities. One of the concerns that comes up quite often is from coaches who question their own qualifications and abilities to work with kids who have disabilities. There is a perception that you must be a specialist of some kind to coach kids with disabilities. Fortunately, this is not a correct perception.

What a coach needs is to truly appreciate the unique qualities of all children. When the good coaching techniques and positive principles promoted by the NYSCA Coaches Code of Ethics are applied, youth sports coaches can include all kids. When additional information is required about a particular child's need for assistance to be successfully included, there are people – family members, professionals and volunteers – who can be consulted about making specific adaptations or accommodations. Some of those resource people may include family or friends of the child, a therapeutic recreation specialist, a physical therapist, or the child's teacher.

What kinds of adaptations, assistance, or accommodations might need to be made? Making an adaptation or providing individual support is done based on the individual child's need for assistance to be successfully included. Sometimes it means making an exception in the rules or altering how one particular activity of the game is performed by that one child based on his or her skills and abilities. For example, sometimes it is as simple as allowing a player who uses a wheelchair to have a "pusher" to assist with base running. This means that two players are together running the bases, and it is made clear that the child using the wheelchair is the player to be tagged out, not the "pusher," because the pusher is simply providing the leg power.

Sometimes the accommodation is utilizing some adapted equipment, like a bright yellow basketball so a child who has a visual impairment can more effectively see the ball during play. This alteration is made to assist the child to have a more equal opportunity for successful participation.

Accommodations and supports are not designed to give the child with a disability or his team an unfair advantage. Rather, they are designed to



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CHILDREN WITH DISABILITIES IN YOUTH SPORTS

continued from page 6

remove the barriers to participation that put that child and his team at an unfair playing disadvantage. Keep in mind that there are no universal sports adaptations that work for all kids with similar disabilities. Each player is unique and the accommodations made need to address individual needs.

Including children with disabilities in typical youth sports activities can be a positive experience for everyone. The most important positive impact is on the child with a disability. This inclusive participation also helps other kids on the team and their families to recognize and appreciate the differences we all have and to value all individual contributions to the total youth sports experience.

A variety of creative ways can be used to include full participation in, and enjoyment of, leisure and recreational activities, too.

Including kids with disabilities in activities with their peers who do not have disabilities is a major guiding principle of the Americans with Disabilities Act. This law provides us with an opportunity to truly welcome all children into youth sports. Coaches are the "key players" that can make youth sports participation enjoyable, successful, and accessible to ALL children.

Cynthia K. Burkhour, M.A. is a Certified Therapeutic Recreation Specialist in Jenison, Michigan and Coordinator of the TASH Leisure and Recreation Interest & Action Group. The Leisure and Recreation I & A Group is organizing an Integrated Sports Roundtable discussion at this year's TASH Annual Conference. One of the goals of the session will be to take a more active role in planning opportunities that are inclusive, and holding discussions with Special Olympics, Inc.

If you are interested in participating in such a forum, or would like to discuss other ways of including all children in youth sports programs, contact Cyndy Burkhour at 616-669-9109 or send her an e-mail at accessrecreationgroup@juno.com

Keep in mind that there are nc universal sports adaptations that work for all kids with similar disabilities. Each player is unique and the accommodations made need to address individual needs.

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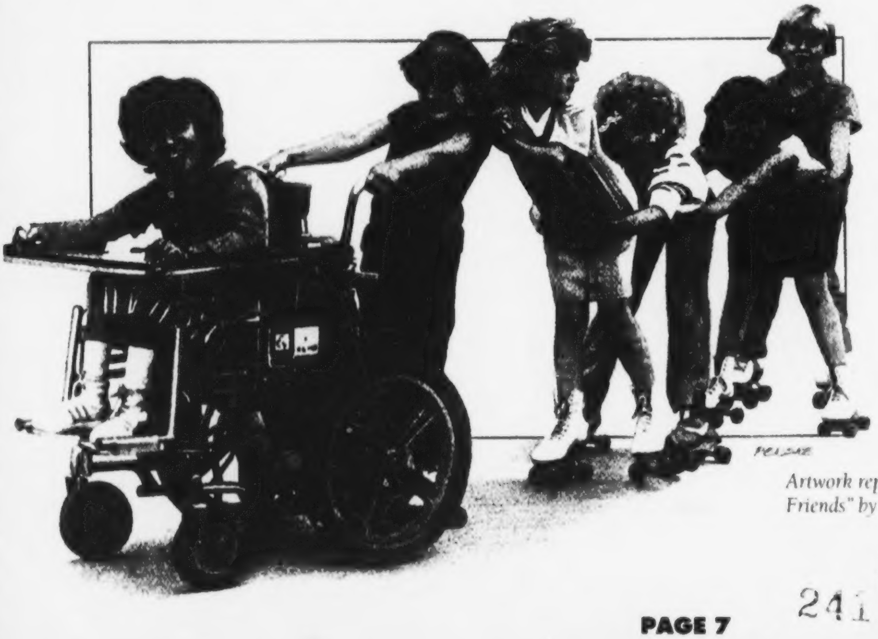

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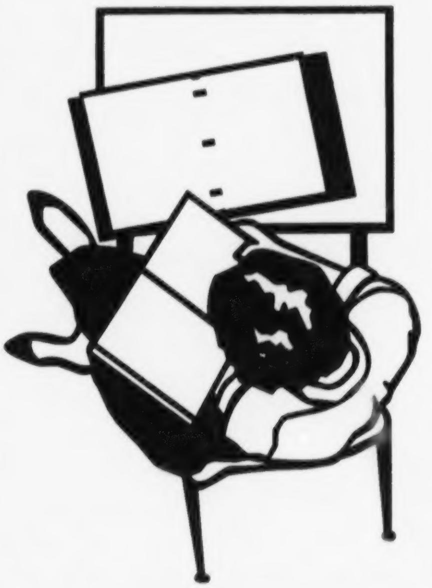
Inclusion *as a* FORCE *for* School Renewal



BY JOHN O'BRIEN AND CONNIE LYLE O'BRIEN

Inclusion Heightens Awareness of the School as Community

Including students with substantial disabilities in regular classrooms heightens awareness of each interrelated aspect of the school's life as a community: its boundaries, its benefits to members, its internal relationships, its relationships with its outside environment, and its history (Taylor, 1992). As most people who have faced the possibilities of inclusion know viscerally, this heightened awareness usually comes in the form of fear and defense, expressed in terms that sound similar from either side of the boundary that separates students on the basis of disability. The art of facilitating inclusion involves working creatively with this state of heightened awareness to redirect the energy bound-up in fear toward the kind of problem solving that promotes reconsideration of boundaries, relationships, structures, and benefits.

Inclusion is a Cultural Force for School Renewal

The students, parents, teachers, and administrators who actively engage in the day-to-day renegotiation of school boundaries, relationships, and structures in order to include students with substantial disabilities represent a powerful cultural force for school renewal. Positive effects of inclusion on school renewal come only when the people engaged (1) notice discrepancies between what they want to do and what current boundaries, relationships, and structures allow and (2) adapt those boundaries, relationships, and structures to make their next steps possible.

Inclusion's potential for school renewal is easily blunted. Involved people can breathe a sigh of relief when a student with a disability simply manages to be present in class without precipitating any of the anticipated disasters, and then raise no further questions about the school's practice. The weight of a school's history—customary labor demarcations, jealousies over resource allocation, rivalries for control, habitual animosities, cynicism, overcommitment to too many reform programs at once—can overwhelm the school's capacity to adapt to the possibilities raised by the practice of inclusion.

For Inclusion to Thrive, Schools Must Be Conscious Communities

People who make up a school that strives for belonging, mutual caring, and commitment to work hard with common purpose have far stronger foundations for their academic work than those who understand their school as a mechanistic organization and treat one another, and the school itself, as though teachers and students were (or ought to be) interchangeable, unfeeling parts that either mesh properly or get junked.

If it is to be achieved at all, community in school must be conscious. No one who is actually working to build community will confuse community with utopia. Communities can stratify themselves and justify terrible inequalities in access to resources. Guiding a school's development is not about invoking community as a magic word. It is about struggling courageously and thoughtfully together for respectful relationships, equality of opportunity for individual initiative, mutual support with life's troubles, ways

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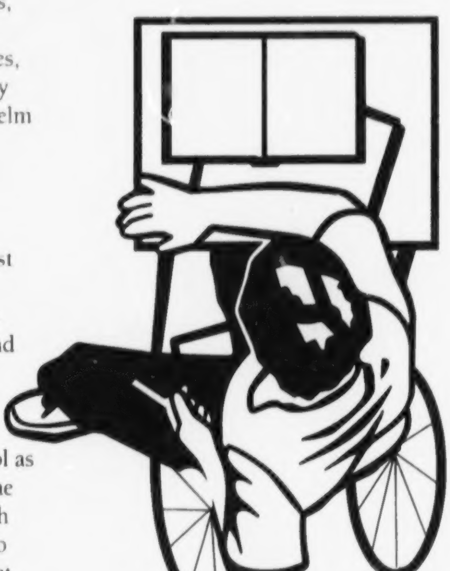

The kind of learning that builds community can only come by choice.

Inclusion *as a* FORCE *for* School Renewal

continued from page 8

to share and celebrate each member's unique gifts, just ways to deal with conflicts, and powerful ways to confront threats with integrity.

The full promise of inclusion lies in the kind of school community that can grow as students with substantial disabilities raise awareness of unspoken dimensions of school life and provide opportunities for everyone who shares that life to learn more rewarding ways to be together. Students with substantial disabilities are, of course, neither the only teachers of these lessons of community nor are they the only beneficiaries of schools that are willing to learn from them. But students with substantial disabilities can make a particular contribution to building community in school exactly because their ordinary presence in regular classrooms, vocational education programs, and student activities has been, to most people, unthinkable.

Learning to Build Community Means Linking Person-to-Person Learning to Social Architecture

The image of building community implies a way to do it. Conscious community develops when people thoughtfully relate cycles of person-to-person learning to the elaboration of a social architecture that expresses and supports that learning. The person-to-person learning cycle relates expanded awareness, new personal skills and capabilities, and a deeper sense of purpose. In competent school communities, person-to-person learning shapes the social architectures—the boundaries, relationships, and structures that organize space, time, talents, and money to do the school's work. Through planning with and for the whole school, shared exploration of a deepened sense of personal purpose can clarify the guiding ideas that organize the school's daily life. Through systematic reflection on effective practice, new capabilities can take form in new tools and procedures that disseminate their effects. Through day-to-day problem solving and conflict resolution, expanding awareness can adapt the school's systems to make the work people want to do easier.

. . . students with substantial disabilities can make a particular contribution to building community in school exactly because their ordinary presence in regular classrooms, vocational education programs, and student activities has been, to most people, unthinkable.

The kind of learning that builds community can only come by choice. School leaders can invite the kind of sustained dialogue necessary to clarify important guiding ideas, or they can simply issue a command: "As of now, this school is an inclusive community." Teachers can thoughtfully incorporate new tools into their practice as a way to develop their capabilities, or they can mindlessly run techniques, complain about their lack of magic effect, and proclaim inclusion a failure. School board members can guide a process of systems adaptation that will strengthen the school community, or they can reactively impose an imported reform on their whole system.

Guiding a school's development is not about invoking community as a magic word. It is about struggling courageously and thoughtfully together for respectful relationships, equality of opportunity for individual initiative, mutual support with life's troubles, ways to share and celebrate each member's unique gifts, just ways to deal with conflicts, and powerful ways to confront threats with integrity.

Building Community is Creative Work

One determinant of the scope and depth of person-to-person learning, and the effectiveness of adaptations to social architecture, is people's shared creativity. Ackoff (1991, p. 99) describes creativity as a three step process: (1) identify fundamental assumptions that: a) appear to be self-evidently true, and b) guide ordinary behavior, c) in ways that significantly reduce the range of available choices; (2) deny the validity of the identified assumptions; and (3) explore the consequences of denying these assumptions.

Inclusion of students with substantial disabilities offers rich opportunities to surface and challenge some of the fundamental assumptions whose obviousness to most people may constrain school effectiveness. The surest road to uncovering these fundamental assumptions begins with careful exploration of the conflicts that polarize people around the issue. This sort of conflict presents two key features: it is framed as an either/or choice and the assumptions that shape it contain strong emotions that pull people to one side of the conflict or another and stick them there. Here are three common conflicts that recur in efforts to create more inclusive school communities.

- Inclusion OR Specialized services
- Classroom activities that support social experiences and friendships OR Classroom activities that support acquisition of academic or vocational skills
- Students with disabilities benefit OR Students without disabilities benefit

A background assumption that locks these conflicts into place is that the only possible resolution is the outcome of a win/lose contest: if we have more of the kinds of classroom practices that support

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Inclusion *as a* FORCE *for* School Renewal

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friendships, we must pay for this in declines in skills or academic attainment; if we have more inclusion we must have less of the specialized services students require; if we have greater benefits for students with disabilities, students without disabilities must suffer.

Dialogue about the way people involved in the conflict understand both of its poles is essential to crafting a theme for action that will organize people's work. This theme is not a solution, but a common goal to which people in conflict can commit their energies and a direction to stimulate problem finding and problem solving.

Students with substantial disabilities, as outsiders, can stir these human energies. Some students, teachers, and parents find that welcome, if difficult, lessons rise with these stirrings. Others react to their fear, and fight to maintain control by sanitizing the school room and cleansing it of significant differences. To work well with the messiness, the uncontrollability, the emotion, and the darkness stirred in many adults by the presence of a few children with substantial disabilities, people who want to make inclusive communities need to reflect on what education means, how it can be supported, and how it can be subverted.

Education Is the Way of Becoming a Human Being

No matter how we try to buffer them, our children face the human realities of poverty, sickness, disability, injustice, aging, and death. Indeed, they yearn to confront these realities so strongly that denial stunts their growth as human beings. Parental love and protection, provision of opportunity, discipline, information, and skills offer the young person some of the resources for transforming revulsion, fear, or morbid fascination into important knowledge. Young people, respectful of parental anxiety for their happiness and of parental desire that they live out parental plans, likely find the best way through these hard realities with the guidance of a trustworthy mentor, who truthfully responds to spoken and unspoken but real questions. Being a worthy mentor means courageously entering a conflict between the parent's desire to protect the child from difficulties by exercising control and the young person's desire to learn by directly engaging difficulties and exploring shadows. The journey of human growth may include periods of traveling alone...but every human journey begins and ends, and mostly it progresses, in and through personal relationships whose quality determines the depth of education.

> **The journey of human growth may include periods of traveling alone... but every human journey begins and ends, and mostly it progresses, in and through personal relationships whose quality determines the depth of education.**

Building Inclusive Community Links Schooling with Education

Education leads children and adults out of comfortable routines and into the challenges and the pleasures of drawing on the lessons encoded in human tools and human texts to face life's realities. Education happens in company with others, and the gifts and fallibility of other members of the company shape the extent and the texture of each member's growth. Schooling will offer people more resources for their education when adults and students collaborate to build conscious community to sustain the work of the school, even though this means growing past the myth of complete control of childhood. Students with substantial disabilities and their parents can liberate and organize much creativity in the school community. All that is required is the courage to renegotiate familiar boundaries, relationships, and structures, the constancy to learn the way through the difficulties that arise and the fidelity to renew the sense of community when it is threatened.

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Taylor, P. (1992). Community. In E. Fox Keller & E. Lloyd (Eds.), Keywords in evolutionary biology (pp. 52-53). Cambridge, MA: Harvard University Press.

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This article is taken from a longer paper, "Inclusion as a Force for School Renewal," which is available from the Center on Human Policy. To receive a copy, write to:

ATTN: Rachael Zubal
Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280

••••••

Another version of this larger paper is published in S. Stainback and W. Stainback (Eds.), Inclusion: A guide for educators. Baltimore: Paul H. Brookes Publishing Co.

NEW LIFETIME MEMBERS

TASH welcomes the following new lifetime members:

MARGARET COOPER • KATHLEEN GEE • DOUGLAS FISHER • RAMMLER & WOOD CONSULTANTS

The financial assistance of TASH's friends and supporters enables us to keep abreast of fast-breaking disability-related information on the social, legislative and best practice fronts; use our widely-read publications as resources through which to disseminate this critical information; supplement the cost of membership for individuals who could not otherwise afford to join; and provide financial assistance to self-advocates and family members who would not otherwise have an opportunity to attend TASH's annual conference.

In helping us to meet the needs of our membership and the broader disability community, TASH gratefully acknowledges the support of the following contributors:

Charlotte Campbell • Naomi Lorch • Martha Snell

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As you saw from the August edition of the TASH *Newsletter* - the 1997 TASH Conference is shaping up to very exciting and informative. If you haven't registered or made reservations yet, please do so today! In addition to the hundreds of sessions listed in the tentative schedule, you don't want to miss the following enlightening sessions:

SATURDAY, 12/13/97

9:15-10:15

Playgrounds for ALL Kids!

Cindy Burkhour, Convener, TASH Leisure and Recreation Interest and Action Group

Playgrounds should be for ALL children! They should be designed to stimulate the imagination, challenge the body and encourage interaction between ALL kids. ALL playgrounds should be fun, safe and accessible to everyone. Unfortunately this isn't the case with many existing playgrounds and sometimes not even with new ones. Many times play equipment is set in the "sea of sand" designed to protect kids who may fall and that sand is surrounded by a big border of railroad timbers designed to keep the sand in. This kind of loose safety surface with its border can be very difficult or impossible to negotiate for a child who uses a walker or wheelchair. Was this design meant to intentionally keep kids with disabilities out? Of course not! In the past, some people just never thought about the need for accessibility to playgrounds. Kids with disabilities weren't seen at the playground, so some figured why bother. Some people just didn't realize that they probably weren't there because it wasn't accessible. It's like the field of dreams, "if you build it they will come." If we make our playgrounds fun, safe and accessible, ALL kids will have the opportunity play together.

The Americans with Disabilities Act tells us that all new construction will be accessible to, and usable by, people with disabilities and that programs, services, and activities will be provided in the most integrated setting. What the law doesn't tell us is "how to" design play facilities that are inclusive and accessible while maintaining safety, fun, and challenge for ALL children. It became clear that the Accessibility Design Guidelines of the ADA didn't address design in the outdoor and recreation environments very well because of the many unique characteristics of recreation facilities.

The U.S. Access Board convened an advisory committee charged with developing recommendations for design guidelines for outdoor recreation facilities, including playgrounds. In response to the recommendations, the Access Board has convened a regulatory negotiation committee to develop the final proposed rule for accessibility design guidelines specifically for play facilities. A balance of interested organizations representing people most affected by the rule was assembled with representatives from the playground industry, providers of playgrounds, and people with disabilities. This committee is in the last phase of production of the final rule.

Cynthia Burkhour has actively represented TASH on the Play Facilities Regulatory Negotiation Committee of the Access board. To date, the committee has reached agreement on the technical requirements for accessible design and scoping provisions which describe how and when to apply the technical requirements that address the characteristics of an accessible route and an accessible play component. These technical provisions describe the minimum standard of accessibility. Accessible routes include paths of travel into and around the play facility, as well as onto, through, and off play structures.

Soon the design standards to ensure a minimal level of accessibility to all newly constructed playgrounds will be available. The work as parents and advocates doesn't end there, it only begins. We need to work closely with manufacturers and designers to help them create playgrounds that not only meet the letter of the law but playgrounds that meet the needs of our families. We need to help people responsible for providing playgrounds learn to make accessibility a primary consideration and not an after thought. We need to help others realize and believe it's the right thing to do for all kids. We need to be proactive by volunteering on playground committees at our children's schools and at our community parks. We can make a difference in the future. Ending segregation on the playground will open the doors to social and recreation inclusion for ALL kids! Come to the session at the Annual TASH Conference in Boston for updated information, and let's get started!

SATURDAY, 12/13/97

1:30-12:45

Integrated Sports Roundtable

Cynthia Burkhour and members of the TASH Leisure and Recreation Interest and Action Group

Join us for a continuation of this lively and important discussion. Participants will discuss a plan of action for the TASH Interest and Action Group to shape a future of inclusive recreation opportunities.

Roundtable Discussion with Superintendents and Principals

Time and date to be announced

Tom Hehir, OSEP, has been invited to lead a discussion with superintendents and principals regarding issues of systems change and implementing quality inclusive education programs. Watch for more information in upcoming Newsletters - and feel free to fax or e-mail information to Denise Marshall about topics you would like to see covered in this session. FAX - 410-828-6706, e-mail dmarsh@tash.org

LETTERS TO THE EDITOR

. . . Statements claiming segregation is always wrong and integration always right are completely foolish. . . . The difficulty with the debate over segregated activities is that someone, somewhere, with authority granted from some place determined that on the continuum of human social activity segregation should and would be banned.

. . . The real issue, in my eyes, is not segregation. The real issue is force. Any time a person with a disability is forced to go to Special Olympics, there is a problem. The problem is not Special Olympics, the problem is force. Any time a person with a disability is forced to compete in regular sports because of lack of information or choice, there is a problem. The problem is not integration, it is force. We in human services force our ideals and ideas into the lives of people with disabilities. . . .

In many agencies where I have provided services I noted that there are no segregated activities. Gone are the dances, the banquets, the bowling, the dinners out with friends. These were determined by someone, somewhere with power granted from some place as philosophically wrong. So people who had one social option -- segregation -- ended up having no social options and everyone (but people with disabilities) thinks that there has been progress. The issue that these agencies should have been dealing with is that segregation is an option, but it is only one option. Instead of eliminating an option, their job should be to create a buffet of options from which people with disabilities can freely choose.

. . . Can we please come to realize that as long as our opinions direct the lives of the adults we serve or parent, we have not done our job? I can think whatever I want about Special Olympics. You can think what you want. We will have only done our job when the only opinions and thoughts that matter are of the people, the legitimate minority, who have developmental disabilities. Can we also come to an understanding that discussion is always better than argument, that people with different opinions aren't necessarily bad, that shades of gray are more interesting than either black or white?

— David Hingsburger, Eastman, Quebec, Canada

We continue to receive a number of letters expressing diverse perspectives in response to David Hingsburger's personal reflections on Special Olympics (May 1997 *Newsletter*). While TASH's position in opposition to segregated activities of any kind - whether related to sports, education, employment, community living or any other area - has never wavered, we do respect the right of individual choice and the need to communicate an array of issues considered by individuals in making those choices.

We thank those of you who have taken the time to share your viewpoints.

. . . after the article by Dave Hingsburger, I am uncertain of the values of TASH. Certainly Dave is a great writer and thinker from a self-actualization/psychologist point of view. When does he think the personal, if ever, becomes the political?

The disability community is currently taking a subtle, yet critical shift toward a "choice" perspective, which is disallowing the view of the public image of individuals who are different in some way. Previously the intent of segregation was based on some very negative societal attitudes, and now that the segregation is based on "self-determination" or the building of "pride," are we naive enough to think the public is aware of the change of the intent?

. . . A friend of mine recently returned from a week at Handicamp - the week for people with cerebral palsy. In our phone conversation, he mentioned that he greatly enjoyed horseback riding, that the camp fire was great, and he even knew the words to "Kum By Yah." Am I supposed to put on my rose-colored glasses and feel good that he simply enjoyed himself, or can I feel a sense of regret that after decades of work around inclusion, an individual who lives interdependently, receives no formal services, and works in a very valued position at our state Capitol has no one with whom to recreate during our beautiful Colorado summers? Maybe I should just attend Handicamp and feel the aura of the atmosphere and hope I achieve the conclusion which Dave did at Special Olympics!

— Marcia Tewell, Denver, Colorado

I am one of those people against settings and activities which are congregated and segregated in nature. This is not to say that everything that happens in those kinds of settings is bad. From David Hingsburger's description of the Special Olympics that he attended (May 1997), Hingsburger reminds us of the many good things that can occur for individuals in settings or activities that many people may not agree with.

. . . I recognize that just because an event is segregated does not necessarily taint everything that happens there.

I was moved by Hingsburger's story of Martin Fudge. In fact, it is very hard to argue with anyone who can point out the boost in self-esteem, accomplishment, or pride that a particular service, activity, or setting might engender. . . . In isolation, any one setting might not seem too oppressive. In the greater context, the sum of the parts speak volumes about society's attitudes and feelings toward people with disabilities.

Hingsburger's "Hot Fudge Sunday" forgot about the other 6 days of the week. Many people that I know who compete in the Special Olympics also spend their time living in group homes with other people with disabilities, work in sheltered workshops with other people with disabilities, . . . have friendships that are exclusively with other people with disabilities, and so on. The point is that many . . . people with disabilities live their days, months, years, and entire lives this way. So when someone mentions the Special Olympics or some other segregated, congregated event, I am not responding as an idealogue, but as someone who is viewing the entire context of a person's life.

No single event or activity is responsible for the oppression of people with disabilities. Rather, it is a clear societal pattern that defines oppression. The chain of exclusion is strong. How we involve people with disabilities in our communities serves to strengthen or weaken the links of inclusion and exclusion.

. . . Hingsburger went to the Special Olympics having asked several important questions about the media reports of this event (for example, how were the athletes portrayed?). While these questions were good, many others remain unanswered (or unasked). For instance, . . . did anyone in the past ever say, "Jim is really great at baseball. Let's get him involved in the local little league," or was it more like "Jim is really great at baseball. Let's get him involved in the Special Olympics."?

I sometimes wonder what would happen if all the money, time, effort, volunteers, caring, and love that is put into the Special Olympics were instead put into developing other, more inclusive ways of giving these athletes the same pride of accomplishment. I also wonder why this hasn't happened yet . . . what is stopping us from developing inclusive alternatives in [sports] and other areas of people's lives? Now that's a question that truly deserves an answer.

— Edward Cohle, West Chester, PA

TASH welcomes Letters to the Editor. If you would like to submit an opinion on an issue you've seen addressed in the *Newsletter*, send your correspondence to: Priscilla Newton, TASH *Newsletter*, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204. You can also fax (410-828-6706) or e-mail (pnewton@tash.org) your letter. Letters (or excerpts) may be reprinted in upcoming issues of the *Newsletter* as space allows.

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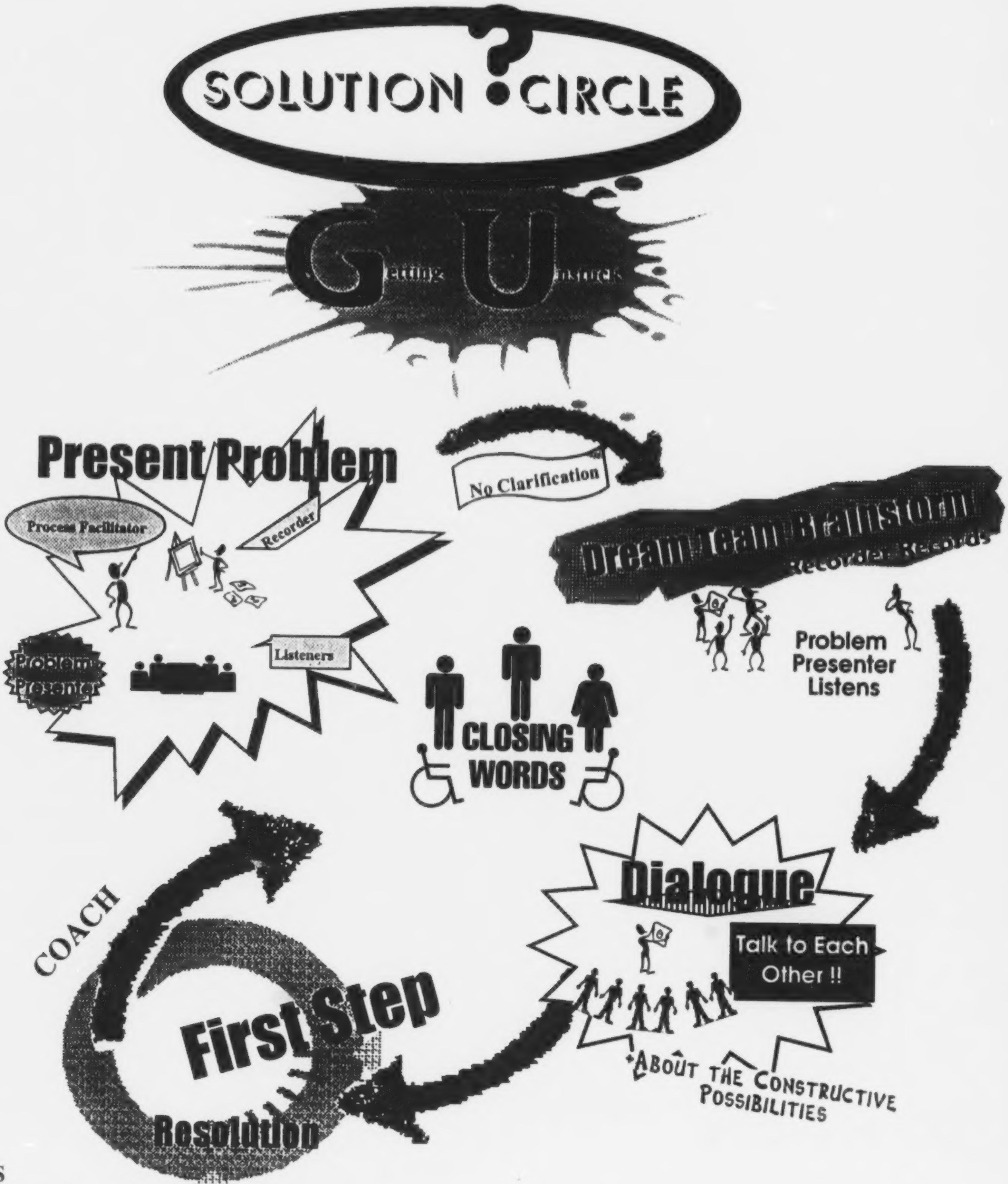


ROLES

- Problem Presenter
- Process Facilitator
- Graphic Recorder
- Brainstorm Team

1st STEP

Dialogue

Move Forward!

Solution Circle: Getting Unstuck: A Creative Problem Solving Tool

DESIGNED BY JACK PEARPOINT AND MARSHA FOREST

The Solution Circle is a short and powerful tool that takes no more than half an hour. It is effective in getting "unstuck" from a problem in life or work. Solution Circles are tools of "community capacity." They demonstrate that people nearby – in any community or work place – have the capacity to help, if asked. It requires a person to ASK - not an easy thing in our culture of privacy and emphasis on "do it alone." This tool puts all the values we and TASH espouse into practice, and demonstrates that TOGETHER WE ARE BETTER.

Time Required:	No more than 30 minutes
People per Solution Circle:	Most effective with 6-12
Roles to be Played:	* Problem Presenter (focus person) * Process Facilitator (team manager, time keeper) * Note Taker or Graphic Recorder * Amazingly Creative Brainstorm Team

Diversity in teams is best: mix the age range and gender of team members.

Explain the steps to the teams in detail:

STEP ONE: (6 minutes) **The problem presenter will have 6 uninterrupted minutes to outline the problem.** The job of the process facilitator is to keep time and make sure no one interrupts. The recorder takes notes. Everyone else (the brainstormers) listens. If the problem presenter stops talking before the 6 minutes elapse, everyone remains silent until the 6 minutes pass. This is key!

STEP TWO: (6 minutes) This is a brainstorm. **Everyone chimes in with ideas about creative solutions to what they just heard.** It is not a time to clarify the problem or to ask questions. It is not a time to give speeches, lectures, or advice. The process facilitator must make sure this is a brainstorm. Everyone gets a chance to give their ideas. No one must be allowed to dominate. The problem presenter listens without interrupting. He/she must not talk or respond. We often give the person masking tape to facilitate their listening. It's hard to just listen!

STEP THREE: (6 minutes) **Now the group can have a dialogue led by the problem presenter.** This is time to explore and clarify the problem. Focus on the positive points only and not on what can't be done.

STEP FOUR: (6 minutes) The First Step. **The focus person and the group decide on first steps that are doable within the next 3 days.** This is critical! Research shows that unless a first step is taken almost immediately, people do not get out of their ruts. A coach from the group volunteers to phone or see the person within 3 days and check to see if he/she took their first step.

Finally, the group does a round of words to describe the experience and the recorder gives the record to the focus person. If it's a large group, the teams return to the main group, debrief and continue.

In our experiences, people love this exercise and find that it generates action. It does not guarantee a solution, but it usually gets people "unstuck" and at least points to the next logical step.

Try it out and let us know how it works for you!

Share the results of your Solution Circle! Contact Marsha and Jack c/o Inclusion Press International, 24 Thome Cres., Toronto, Ontario M6H 2S5 CANADA. Telephone (416) 658-5363, fax (416) 658-5067, e-mail: 74640.1124@Compuserve.com, or visit Inclusion Press International's web site: http://Inclusion.com [New Stuff]

INCLUSION RESOURCES

NEW BOOK FOR 1997!

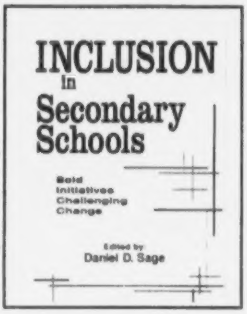
INCLUSION in Secondary Schools

Bold Initiatives Challenging Change

edited by:

Daniel D. Sage, Ed.D.

Although much has been written in recent years regarding the concept of inclusion and its application in the practice of educating students with disabilities, a relatively small part of the attention has been focused on secondary schools. There are, however, a number of secondary settings where some initiatives are being attempted that challenge the status quo of special education philosophy and practice.


INCLUSION in Secondary Schools
Bold Initiatives Challenging Change
Edited by
Daniel D. Sage

This book contains written record of the experiences of those working in such settings. Regardless of the claimed success or acknowledged difficulties associated with these initiatives, there is much to be learned by examining the cases described. A total of 23 authors contributed to the eight chapters that describe a variety of experiences with inclusive efforts at the secondary level.

1997, 272 pages, soft cover	*$29.95*

Keep up with the times!

INCLUSION Times for

Children and Youth with Disabilities

No single issue in school reform has created more controversy or continuing debate than the inclusion of children and youth with disabilities into regular education. The *INCLUSION Times* newsletter assists professionals and parents in obtaining critical information in this regard.

Published 5 times per year -- September/October; November/December; January/February, March/April and May/June -- this newsletter provides the latest information on:

- **best practices and model programs**
- **federal and state initiatives and policies**
- **articles on parent and teacher perspectives**
- **conferences and events**
- **information on how to obtain books, videos and other resources related to inclusion, and much more!**

This informative newsletter is required reading for all individuals interested in a "balanced" presentation on the issues surrounding this controversial movement!

One Year (5 issues)	*$39.95*
Two Years (10 issues)	*$59.95*

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FEATURING THOMAS ARMSTRONG:
on the topic of Teaching Diverse Learners *Nov. 13 - 14, 1997, Baltimore, MD*
***CALL:* National Professional Resources 1-800-453-7461**

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Gay man with disabilities troubled by life's barriers

BY ANNE HARRIS

Shawn Kelly faces a double barrier in life. Gay and disabled, Kelly is caught between service organizations designed with only straight disabled people in mind, and a gay and lesbian community that can't or won't reach out to him. For the past several years, Kelly, 28, who was born with cerebral palsy, has been trying – with no success – to get volunteers from the gay and lesbian community to assist him in attending gay social events.

"The whole experience of getting into the gay community sucks," said Kelly, adding that he has been disappointed again and again by well meaning people who could not deliver on their promises of help.

Accompanied by his aide, Linda Hawkins, Kelly has attended two Human Rights Campaign Fund dinners, and a holiday party at Girth and Mirth, a gay social club in Redford, Michigan.

"We always meet a lot of real nice people, people who were very responsive to Shawn," said Hawkins. "They take his phone number but we never hear from them again."

"They're scared of me because I'm not like them. My speech is hard to understand," said Kelly, explaining why he thinks no one has followed through on their offers to assist him. "But the more you talk to Shawn, the easier it is," said Hawkins. "Once you get the hang of how he enunciates a word, then you can understand him. It takes a little bit of effort, and a lot of people don't want to put the time forward to make that effort."

Hawkins finds it particularly ironic that Kelly has been unable to get help from the gay and lesbian community. "What I don't understand is how people can go through so much hell trying to be accepted, yet not accept someone like Shawn. Why can't people look inside themselves and help him?" she asked.

Shawn Kelly

Realizing that accessing the community is difficult for many gay and lesbian people, with and without disabilities, Kelly and his therapist, Dale Ross, conceived of a Helping Aunt/Helping Uncle program. Mirroring the Big Sister/Big Brother programs, the idea hinged on locating volunteers to introduce people with a new-found gay or lesbian identity to the community.

According to Ross, they first introduced the idea in 1993, although it didn't meet with much initial interest. Ross then presented the Helping Aunt/Helping Uncle program at a meeting of the Detroit Area Gay and Lesbian Council in January 1994. There, Jeff Montgomery of the Triangle Foundation offered to take on the project. Through Triangle, Ross also found a volunteer to take Kelly to some local gay socialization spots.

Unfortunately, these plans fell through. The volunteer dropped out of communication, said Ross, without taking Shawn to any of the places they had discussed. The Helping Aunt/Helping Uncle program stalled.

"It turned out to be quite a big project," said Montgomery. "We didn't have the staff to commit to it and we are sorry about that, but it remains an excellent idea."

> "What I don't understand is how people can go through so much hell trying to be accepted, yet not accept someone like Shawn. Why can't people look inside themselves and help him?"

As Hawkins notes, some of Kelly's trouble in making it out to gay gatherings lies with his service agency. Kelly lives in a small group home managed by Wayne Community Living Services (WCLS).

"WCLS has always been very supportive of persons with disabilities who are gay," said Hawkins. Still, she conceded, "We can't blame it all on the gay community."

Hawkins explained that Kelly must be accompanied when he goes out. Those

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Gay man with disabilities troubled by life's barriers

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most readily available to assist him are the staff at WCLS. "Some staff would not be comfortable going to a gay social function, and if they're not comfortable, Shawn isn't comfortable going with them," she said.

In an effort to help Kelly get out and meet other gay people, WCLS brought gay male staff into his home as aides. But as Hawkins pointed out, staff of WCLS are held to a strict code of conduct. The aides were reluctant to accompany Kelly to gay bars, fearing the loss of their jobs.

"Everything that we hoped that aides would do they were unable to do," said Hawkins. "There's a very strict code of conduct for aides. We cannot involve ourselves in sexual activities at all, and we cannot promote sexual relationships," she added.

One of Kelly's long-held goals is to attend the TNT bathhouse. Kelly has sought a volunteer from the gay and lesbian community to accompany him on an initial visit to get his bearings, so he could then return on his own for additional activities, including making contacts for sex.

"Sex is important for me, since I am a whole human being, including my sexuality," said Kelly.

"One of the myths that go with people with disabilities is that we're not supposed to be sexual. We've made sex a special benefit for the myth of mainstream normal people, and anyone who's too young, too old, or too different isn't supposed to have it at all," said Ross.

Hawkins said she is willing to take Kelly to TNT, but cannot get admitted because she is a woman. "How does that line become so rigid that rather than helping people to stay safe, it ends up hindering them?" she wondered.

Hawkins said that she and Kelly have been asked to leave bars because the proprietors did not think Kelly should be there, or feared that they would be liable if they served him.

"A lot of people think that a person with disabilities is not capable of making their own decisions. They don't realize that Shawn is a 28-year-old adult. He is his own guardian. Nobody is responsible for Shawn but himself," she added.

Reprinted with permission from Between The Lines, May 1997.

TASH Sexual Orientation Interest & Action Group

BY ANN HELER, GROUP COORDINATOR

The issues Shawn so poignantly describes are exactly some of the issues that led to the formation of TASH's Sexual Orientation Interest & Action Group. Sexuality issues are always "sensitive" and recognizing the issues as valid for people considered by the community as "not quite equal" has taken a long time. While we are a lot further than we have ever been, I would agree that we are not yet where we need to be. Paralleling the general community, issues around gay, lesbian, bisexual, and transgender orientation are slowly being addressed. The Sexual Orientation Interest & Action Group's position is let's talk about these issues! Let's figure out how we can address these issues with everyone in our lives in a positive and ethical way.

In 1994, a number of TASH members felt that sexuality issues regarding any group of people TASH advocates for were not being adequately addressed. At the same time, another group felt that gay, lesbian, bisexual, and transgender issues were also not being addressed or even recognized. This was articulated in a Gathering session led by Michael McSheean. In 1995, TASH changed its organizational format and the Sexual Orientation I & A Group was formed. We are under the umbrella of the Community Living Open Project Groups and participate in their annual Gathering.

The goals of the Sexual Orientation I & A Group are straightforward:

- encourage presentation proposals around sexuality issues for each annual conference;
- encourage TASH to articulate more clearly its commitment to sexual diversity as a valid choice for everyone;
- make the annual conferences comfortable for people of all sexual orientations; and
- disseminate information and resources.

Last year there were 5 presentations on sexuality issues, including two speaking to gay, lesbian, and bisexual issues; a no-host hospitality hour; a dinner at a local gay-owned restaurant; and a meeting of the Sexual Orientation I & A Group. This year, we have about the same range of presentations and events, but we are not sponsoring a dinner. Also, David Hingsburger will be back both as a keynote speaker on Thursday and as a presenter on Friday, and Matt Sturiali from Young Adult Institute will address consent issues when traditional methods of ascertaining consent are not possible. Both were requested by conference attendees last year.

Issues that will be addressed this year by the Interest & Action Group include:

- community responsibility and sexuality issues when the people involved are not traditionally able-bodied both in the general and in the gay/lesbian/bisexual/transgender communities;
- strategies to assist gay/lesbian/bisexual/transgender community organizations to include the not traditionally able-bodied; and
- opening a dialogue with national gay/lesbian organizations on disability issues.

We welcome everyone to attend the presentations and the Group's meeting. Dates and times for all of the presentations and the Sexual Orientation Group forum will be listed in the conference program.

If you are interested in joining TASH's Sexual Orientation Interest & Action Group or have questions, please contact:

Ann Heler c/o Moses Field Center - WCRESA
1100 Sheridan • Detroit, MI 48214
Voice: (313) 579-1008 • E-mail: helera@mail.wcresa.k12.mi.us

Supported Living Resources

BY KATHY HULGIN AND PAM WALKER

This article features annotations of some key materials related to supported living. Supported living has developed over the past 10 years or so as the practice of supporting people, including those with severe disabilities, to live in their own homes, gain control in their lives, and to become valued members of their communities. The materials featured below include: (1) general materials and resources about the concept and practice of supported living; and (2) descriptions of specific supported living implementation.

What Is Supported Living: General Supported Living Resources

- O'Brien, J. (1993). Supported living: What's the difference. Syracuse: Center on Human Policy.

In this article, O'Brien distinguishes between supported living and other service approaches. He argues that understanding supported living requires a reconsideration of assumptions and behavior toward people with disabilities. The article begins with descriptions by service providers who have pioneered the approach of experiences which have enabled them to step outside the assumptions and practices that usually govern service providers. This is followed by the identification of issues that should govern supported living services and a concluding list of the obligations of service providers to individuals and their friends and families.

- IMPACT: Feature issue on supported living, Volume 8(4), Autumn 1995. Minneapolis: Institute on Community Integration and the Research and Training Center on Residential Services and Community Living, University of Minnesota.

In this issue of IMPACT, leaders in the development of supported living describe the challenges, issues, and accomplishments of this movement. Articles describe: what supported living is; use of Medicaid funds and supported living services; moving from philosophy to practice; as well as a number of supported living implementation efforts from state, local, and individual perspectives. Also included are annotations of numerous resources related to supported living.

- Hulgin, K. (1996). Innovative practices in supported living: An overview of organizations, issues, and resource materials. Syracuse: Center on Human Policy.

This is a compilation of a wide variety of resources related to supported living. It begins with an introduction to the concept of supported living. Next, descriptions are provided of a number of agencies across the country that offer supported living services, including some that have converted to supported living from more traditional service apprroaches. The following section outlines several considerations in implementing supported living, including: housing support, person-centered planning, individualized funding, and service brokerage. A final section contains annotations of numerous written materials related to supported living, as well as descriptions and contact information for resource organizations.

- O'Brien, J. & Lyle O'Brien, C. (1991). More than just a new address: Images of organization for supported living agencies. In V.J. Bradley, J.W. Ashbaugh, & B.C. Blaney (Eds.), Creating individual supports for people with developmental disabilities (pp. 109-140). Baltimore: Paul H. Brookes Publishing Co.

In this chapter, O'Brien and Lyle O'Brien explain the need for new ways of thinking about organizations and or organizing to implement a supported living approach. They explain that supported living involves a new mindset in working with people, one which is not compatible with many existing service organizations. More responsive organizations will facilitate positive relationships with people receiving services and the opportunity for continuous learning from the effort to support them. The chapter includes ideas for building new structure and uses of power within agencies. For example, it describes a new way of building effective teams and responsibilities of directors. The chapter concludes with a discussion of the need to view organizations as social units rather than the traditional machine image if these changes are to be implemented successfully.

- O'Brien, J., & Lyle O'Brien, C. (1995). Living with the questions Notes from a gathering of people concerned with supported living. Syracuse: Center on Human Policy.

This report was generated from a gathering of innovators in the supported living movement including: people with disabilities, family members, service providers, and system managers. Participants of the gathering drew upon their experiences to describe issues related to supporting people to live in their communities. Their experiences provide an in-depth understanding of this process. Topics include contradictions with system

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Supported Living Resources

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rules, how support makes a difference in people's lives, concerns in the day-to-day work of service providers, and strategies for growth of supported living. The report ends with reflections by several participants.

Supported Living: Agency Examples

- Hulgin, K. (1996). Jay Nolan Community Services: The Advantages and Dilemmas of Converting Quickly from Group Homes to Supported Living Services. Syracuse: Center on Human Policy.

Jay Nolan Community Services is a nonprofit organization that provides a range of services to people with autism and other developmental disabilities in Los Angeles, California. Since January 1993, this agency has made remarkable changes in the way that is provides residential services. It has moved from operating group homes to supporting people to live in their own homes. This report, based on a visit in November 1995, describes this process of change.

The first section outlines the agency process of transition from group homes to supporting people in their own homes. This section includes a discussion of significant opportunities and strategies that contributed to the agency's success in this relatively quick change process, including: (1) learning from other agencies that had been successful in developing supported living services; (2) cultivating the commitment and skills of a team of staff; (3) clarifying issues related to decision-making power; (4) giving families opportunities to learn about supported living; and (5) agreeing to shift to supported living services without asking for increased state funding.

The following section describes ways in which the agency has begun to identify and respond to the needs and preferences of individuals over the long term, including: implementing circles of support; rearranging staff responsibilities; providing continuous opportunities for learning; and working to gain system support. Another section describes some specific changes that have occurred in a few people's lives. And the report ends with a summary of lessons that have emerged from implementing a supported living approach in this agency.

- Kiracofe, J. (1994). Strategies to help agencies shift from services to supports. In V.J. Bradley, J.W. Ashbaugh, & B.C. Blaney (Eds.), Creating individual supports for peole with developmental disabilities (pp. 281-298). Baltimore: Paul H. Brookes Publishing Co.

This chapter draws upon the experiences of "change agents" at the Human Services Institute (HSI) in Maryland in their work to help agencies move from traditional modes of services to an individualized support approach. The chapter begins with an examination of the factors or characteristics of an agency that indicate a willingness to change. Next, various levels of change are described, including: change in structure, change in technology, change in behavior, and changes in values and assumptions.

The chapter then outlines eight elements or steps of successful agency change: (1) establishing commitment; (2) building ownership of key stakeholders; (3) setting the tone; (4) trying a new way; (5) reflecting and sharing; (6) follow-up training and consultation; (7) analyzing findings and implications; and (8) developing an action plan for constructive change. This is followed by descriptions of the process of change within two agencies.

- Klein, J. (1992). Get me the hell out of here: Supporting people with disabilities to live in their own homes. In J. Nisbet (Ed.), Natural supports in school, at work, and in the community for people with severe disabilities (pp. 277-339). Baltimore: Paul H. Brookes Publishing Co.

Through a compilation of personal stories, this chapter describes the provision of community supports for adults with developmental disabilities developed by a residential support program in Greeley, Colorado. The first section outlines Jeanne's story of transition from an institution to her own home. Next, a brief historical background of the evolution of residential services in provided, as well as a discussion of this program's transition from providing residential services to residential supports. The fourth section contains Karren's story as further illustration of various supports. This is followed by a section which proposes a set of values for residential support. The sixth section outlines the process for developing residential supports, using Sharon's story as an example. Finally, the chapter concludes with an examination of what has been learned from this approach to providing supports and implications for future directions.

- Walker, P. (1995). From a community residence to a home of their own. Syracuse: Center on Human Policy.

This monograph describes the process that enabled two women to move from a community residence to a home of their own. It discusses agency efforts that facilitated the process. The report gives detailed information on the agency's collaboration with a community housing agency and how the purchase of the home was financed and approved. In addition, the report describes the supports that were arranged to assist the women to live in their new home and the changes the agency made in thinking about supports for people in their own homes versus agency-operated facilities.

- Chernets, G. (1995). Innovation in the way people with disabilities can be supported to live and participate in community life. In L. Nadel & D. Rosenthal (Eds.), Down syndrome: Living and learning in the community (pp. 256-262). New York: Wiley-Liss, Inc.

This chapter, written by a parent of three daughters, two of whom have disability labels, describes the development of two housing cooperatives and a support organization which works in conjunction with cooperatives to support members with disabilities. The co-ops—Courtyard and CHORD—are committed to creating welcoming, inclusive, supportive communties representing people of various ages, income levels, abilities, and

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Supported Living Resources

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cultural origins. The support organization, NABORS, works in conjunction with the co-op communities. In addition to describing the philosophy and organizational structure of the co-ops and NABORS, the author discusses some of the experiences of her daughter within the co-op.

Kathy Hulgin is Research Associate at the Institute for the Study of Developmental Disabilities, Indiana University; Pam Walker is Research Associate at the Center on Human Policy, Syracuse University.

The preparation of this article was supported in part by the National Resource Center on Community Integration, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133D50037. No endorsement by the U.S. Department of Education should be inferred. The Center on Human Policy subcontracts with TASH for space in this *Newsletter*.

DESIGN FOR CHANGE

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This four day workshop will offer a small group intensive time to work together on designing and facilitating change.

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VOLUNTEER ALERT!

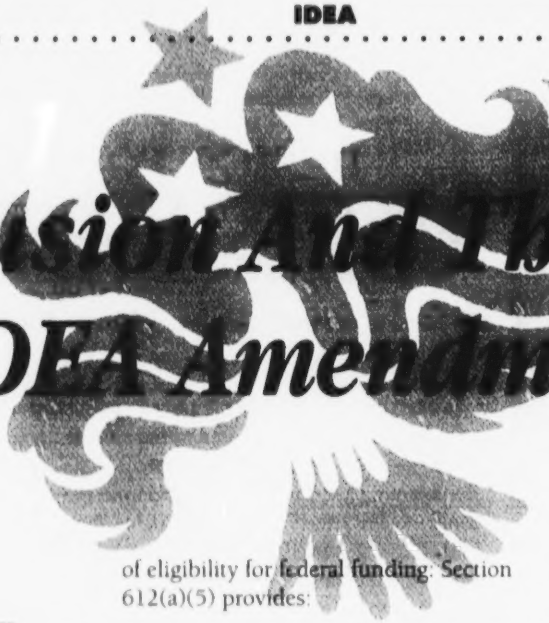
With the TASH annual conference just around the corner, it's time to once again call upon the dedicated individuals who work so diligently to help us keep the conference organized and running smoothly.

YOUR SERVICES ARE URGENTLY NEEDED!

Whether you've participated as a volunteer before, or would like to do so for the first time, we welcome your assistance.

If you would like to attend the conference and save on registration fees, this is the "ideal deal" for you! Volunteers donate a minimum of 10 hours of service during or just prior to the conference in exchange for complimentary registration to attend conference sessions during your non-volunteer periods.

If you are interested, please contact Priscilla Newton at 1-800-482-8274, ext. 102 or e-mail her at pnewton@tash.org to request a volunteer registration form.



Inclusion And The 1997 IDEA Amendments

BY FRANK LASKI

Three years ago there were indications that teachers'unions, school associations, and some representatives within the disability community would use the IDEA reauthorization process to urge the Congress to revisit the 1995 IDEA integration imperative that children with disabilities be educated together with non-disabled children whenever possible. Some groups claimed that the movement for full inclusion needed to be moderated and that separate classes, and even separate schools, for some children should and could be given legislative legitimacy by the "Contract with America" Congress.

However, as the reauthorization process evolved to the final formulation of the Individuals with Disabilities Education Act Amendments of 1997, signed by President Clinton on June 4, 1997, there was no equivocation or weakening of the strong Congressional preference for full inclusion. The Congress not only reaffirmed the 1975 mandate, but in several substantive provisions, strengthened the federal statutory requirements for inclusion. The IDEA Amendments now enable parents to hold schools accountable not only for conducting an IEP and placement process that fairly considers regular class placement, but also for providing the services in the regular class that will make inclusion effective.

The 1997 IDEA Amendments preserve without change the fundamental interpretive requirements as a condition of eligibility for federal funding: Section 612(a)(5) provides:

"to the maximum extent appropriate, children with disabilities . . . are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of the child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."

The Senate Report makes clear that the re-enactment of this federal obligation is purposeful and serious. The Report states "the Committee supports the long-standing policy that, to the maximum extent appropriate, children with disabilities are educated with children who are non-disabled. . . ."

Recognizing that many state funding formulae based on category of disability provide incentives for local districts to place children in handicapped-only classes and schools, Congress imposed an additional eligibility requirement by which states must assure that funding formulae do not result in segregated placement and states revise non-compliant funding schemes as soon as feasible.

The integration requirement applies as well to early intervention services. Section 632(4)(g) states that "early intervention services must – to the maximum extent appropriate – be provided 'in natural environments, including home and community settings' in which children without disabilities participate."

Most importantly, the 1997 amendments add new requirements to the IEP that will effectuate the full inclusion of students now in separate classes or only partially integrated. In addition to the requirements in current law, each IEP must include

> (iii) a statement of the special education and related services and supplementary aids and services to be provided to the child, or on behalf of the child, and a statement of the program modifications or supports for school personnel that will be provided for the child—

Supplementary aids and services are to be provided to the child to accomplish for the child three educational purposes, now stated in IDEA

- "to advance appropriately toward attaining the annual goals"
- "to be involved and progress in the general curriculum and to participate in extracurricular and/or non-academic activities" and
- "to be educated and participate with other children with disabilities and non-disabled children."

By statutorily defining "supplementary aids and services" and directing that they be provided to meet both IEP goals and general curriculum goals, the new amendments should put an end to the practice of putting to parents a Hobson's

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Inclusion and the 1997 IDEA Amendments

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choice* of inclusive placements for socialization versus segregated placements for academic progress. Both progress on IEP goals and progress in the general curriculum are equally important, and the provision of supplementary supports must be directed to the accomplishment of both.

The new requirement that each child be involved and progress in the general curriculum makes it impossible to comply with the federal law by simply offering a limited set of services provided in predetermined, categorical settings and formats. Under the 1997 Amendments, not only are self-contained classes suspect, but self-contained IEP goals, objectives, and activities are suspect, as well. The Committee Report describes how far-reaching the new requirements are in the necessary involvement of regular education and regular education in the IEP process. Among the Committee explanations are

- "This language require[s] that the IEP's annual goals focus on how the child's needs resulting from his or her disability can be addressed so that the child can participate . . . in the general curriculum offered to all students."
- "The Committee wishes to emphasize that the 'support' for school personnel, which is stated in the child's IEP, is that support that will assist them to help a particular child progress in the general education curriculum."
- "[The IEP team] can include personnel knowledgeable about services that are not strictly special education services, such as specialists in curriculum content areas such as reading."
- "The Committee believes that a number of considerations are essential to the process of creating a child's IEP. The purpose of the IEPs is to tailor the education to the child, not tailor the child to the education.

●

> *The Congress not only reaffirmed the 1975 mandate, but in several substantive provisions, strengthened the federal statutory requirements for inclusion.*

●

The 1997 Amendments for the first time give the regular education teacher of the child a central role in the IEP process. Section 614(d)(2)(C) states

"The regular education teacher of the child, as a member of the IEP team, shall . . . participate in the development of the IEP including . . . the determination of supplementary aids and services, program modifications, and support for school personnel."

The amendments bring the IEP team back to its original and honorable purpose – to enable parents to confer with teachers knowledgeable about the general curriculum and the design and delivery of instruction in the regular classroom. There is little need or role for school IEP representatives whose job is to process IEP's and whose knowledge base is paper compliance.

The 1997 Amendments adopt the previous requirements set forth in inclusion cases such as Oberti and Holland: to hold schools accountable for seriously considering supplementary aids and services before excluding a child from regular class. Each IEP team must include in its deliberations

"an explanation of the extent, if any, to which the child will not participate with non-disabled children in the regular class and in [extracurricular and other non-academic activities]." Section 612 (d)(I)(iv)

A check mark in a box at the end of an IEP or the application of a note formula for non-curricular time in the presence of non-disabled children will not pass muster under the 1997 Amendments.

When it comes to inclusion, the 1997 Amendments are remarkably clear and should prove helpful to securing necessary supports and services for children in regular class.

- By outlawing funding formulas that lock special education resources in separate settings, Congress has addressed a major systemic barrier to full inclusion.
- By strengthening the role of regular education teachers and parents in the IEP process, the Congress has addressed legitimate professional concerns about inclusion.
- By mandating supplementary aids and services and broadly defining services and supports, the Congress has made it possible for each child to be included.

In sum, under the 1997 Amendments, nickel and dime mainstreaming is out; full inclusion with full support for regular educators is in.

* A situation in which there appears to be choice but in which, in reality, no choice exists.

Look for an upcoming TASH *Newsletter* containing a comprehensive analysis of the 1997 IDEA Amendments, with detailed examinations of discipline issues, promising practices, and more!

Complexities of Community Building Workshop

BY DENISE MARSHALL

It was a hot and muggy day in Syracuse, NY on July 15th, 1997 when 179 people from 3 countries and 18 states gathered at the Genesee Inn for the workshop co-sponsored by The Center on Human Policy and TASH. It was truly a great opportunity for the community gathered to not only learn and discuss strategies for community building, but to work together to overcome a broken air-conditioner and other accommodation hurdles at the conference location! Fortunately, attendees seemed to be successful on both fronts.

Here are some of the successes and hot topics that attendees reported:

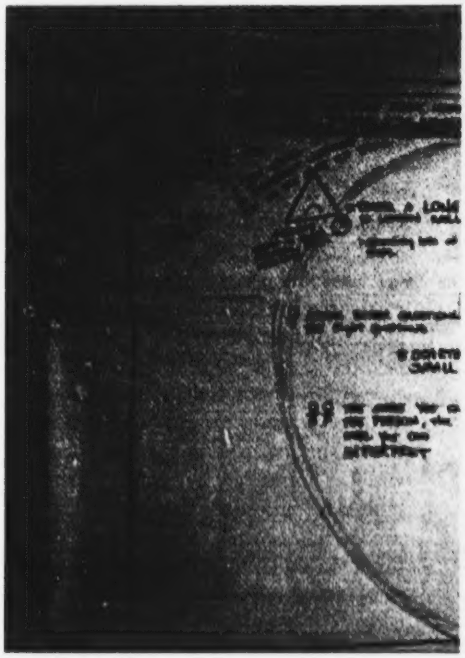
- Story telling and sharing by participants
- Discussion of philosophy of "people being people" and "equality of being"
- Community building is not just a concept - it takes dedication, support, and caring to happen
- Lessons learned on how to overcome problems and hurdles
- Discussion of an opposite concept - how not to get in the way of community building!
- The importance of learning to listen to others
- Span of focus is on individual, agency, and system
- Thinking differently about community, commitment, and promise for oneself and others
- The answers are within each of us; individually and collectively we can creatively problem solve and make it happen!
- Group sharing in an unstructured, free-flowing way works well for some, and others need more guidance and facilitation - have a good mix of both to get the maximum out of people
- Idea sharing is great - but make sure you end with a first step people can implement

Beth Mount

Although the discussion and learning was great, the consensus was there is still much to learn and process regarding this very complex, yet rewarding, issue. Some of the topics that continue to be of concern to attendees include:

- Next steps for advocacy efforts in systems change
- What are the dangers of person-centered planning and how do we deal with them?
- Hearing how specific problems are worked through
- The tension between "rights" and "relationships"
- Linkages to other established community grassroots efforts
- How to address state regulatory issues as they relate to person-centered planning
- Evolution of the deeper meaning of community
- The roles of support staff people in building community
- Creating the capacity to change attitudes

If you have a story to share that gives insight or shares learning in an area of Community Building , please feel free to submit it to Priscilla Newton, TASH, 29 W. Susquehanna Ave, Suite 210, Baltimore, MD, 21204, or pnewton@tash.org for consideration of publication in an upcoming TASH *Newsletter*. For more information on this topic or the information generated at this workshop, contact the Center on Human Policy National Resource Center at 1-800-894-0826.



Map drawn by Beth Mount lists some of the issues, complexities and difficulties encountered in building communities.

TASH would like to sincerely thank Steve Taylor and all the Center on Human Policy Staff, John and Connie O'Brien, and Beth Mount for their time, wisdom, and ongoing support of TASH.

For those who attended the conference, the Center on Human Policy and TASH offer their sincere apologies for the discomfort experienced by conferees due to the quality of the facilities. TASH is following up with management and owners of the Genesee Inn in Syracuse to lodge a formal complaint, and possibly civil action concerning the lack of accessibility, ineffective air conditioning units, lack of restroom facilities, and several other issues.

If you want to contact the Genesee Inn directly, the address is 1060 E. Genesee Street, Syracuse, NY 13210. Please provide TASH with a copy of your correspondence.

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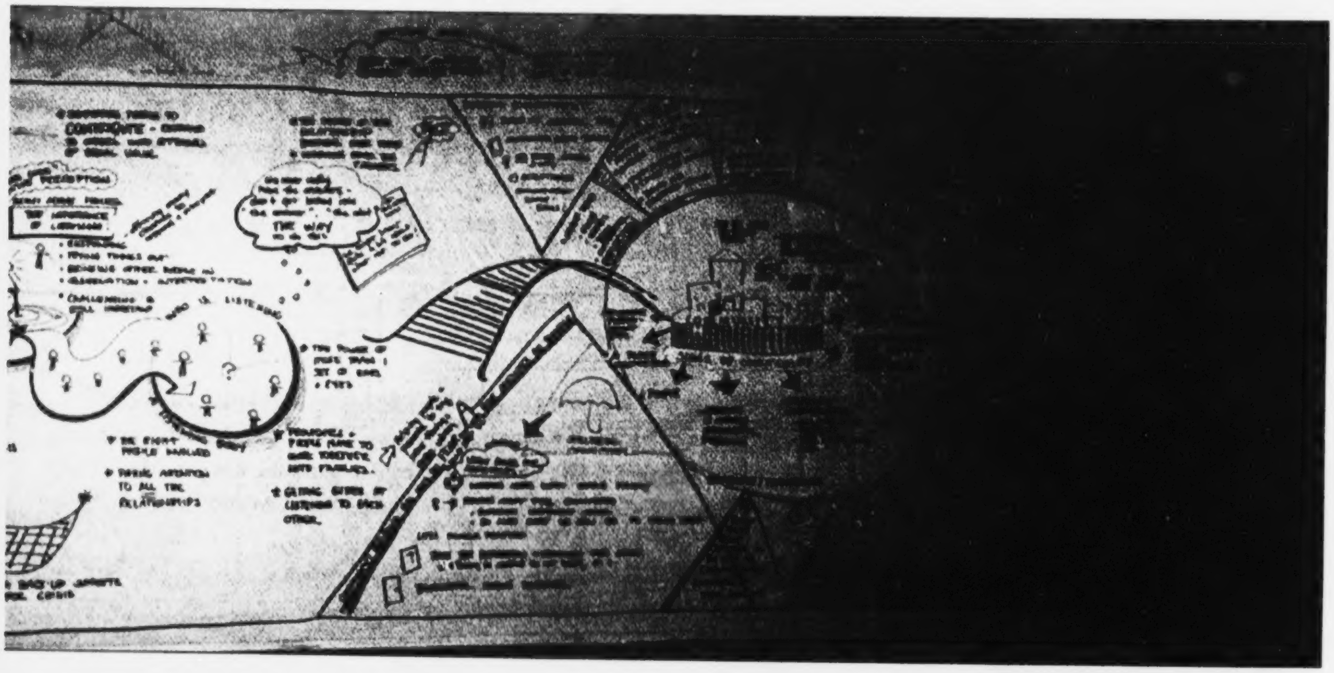
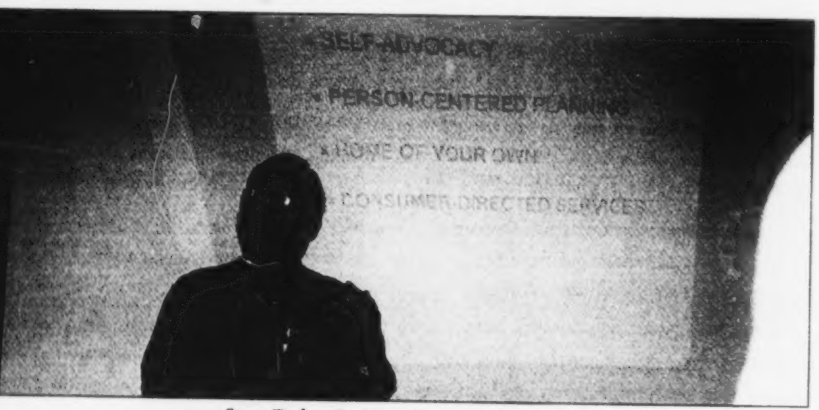


Personal storytelling by participants during the workshop

Connie Lyle O'Brien and Beth Mount leading discussion.

John O'Brien, Workshop Facilitator



Steve Taylor, Center on Human Policy

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Judge Rotenberg Center Receives Court Protection

DMR Commissioner resigns as receiver takes the reins

REPORTED BY HERB LOVETT

The Commissioner of Massachusetts' Department of Mental Retardation (DMR), Philip Campbell, resigned on March 6 following a decision by the Supreme Judicial Court that his management of the Judge Rotenberg Center was improper. The JRC (also known as the Behavior Research Institute or BRI) uses electric shock and other painful aversives as "therapy" for people with behavioral difficulties, most of whom have autism. The court held that DMR, which funded JRC programs, had improperly attempted to put this vendor out of business by "interfering" in its fiscal operations.

This represented a setback for all who have been fighting in Massachusetts to make the Commonwealth an aversives-free zone. So far, JRC/BRI has been remarkably successful in blocking legislation to ban the use of aversives, as well as to evade ordinary oversight by the state Department of Mental Retardation.

JRC/BRI has had 5 deaths under unusual circumstances since 1980. The latest, that of Linda Cornelison, had gone unreported for several years. Ms. Cornelison died after having been visibly ill and in distress for several days from what was later revealed as a gastroenterological condition. In the days before she died, she was pale, disoriented, had "glassy eyes," and kept attempting unsuccessfully to vomit. During this time, staff mistook her attempts to communicate her pain and discomfort for "target behaviors" and she was punished repeatedly with spankings, finger pinches, muscle squeezes, forced inhalation of ammonia, and taste aversives. On the day she died, she received a total of 61 aversives.

The report into her death by the Disabled Persons Protection Commission and the Massachusetts Department of Mental Retardation concluded that her treatment had been "inhumane beyond all reason" and constituted not only violations of legal standards but of "universal standards of human decency."

In the course of his six years of service, Commission Campbell's dedication to the cause of quality services for people with developmental disabilities led him to increasing community and family supports while decreasing the number of citizens in state "schools." TASH and the Autism National Committee join those who regret his departure and hope his successor, Gerald J. Morrissey, Jr., is prepared to maintain and pursue high standards of social justice and community support for all citizens.

Governor William Weld, who recently resigned to pursue a national post, said in a press interview that they found no cause for alarm in the use of aversives on people with disabilities. Three weeks later, he signed a proclamation naming March as Applied Behavior Analysis month.

Curiously, on May 9th the Governor issued yet another proclamation praising former Commissioner Campbell for his leadership in supporting self-advocacy, helping people with disabilities to live in their communities, reducing the waiting list, and promoting supported employment and other "innovative programs."

Meanwhile, 44 people with disabilities, mostly young, are currently being "treated" at JRC. We will not rest until this stops.

Following the Court ruling, JRC's court-appointed receiver, Lawrence T. Perera of Hemenway & Barnes, Boston, issued an open letter stating that "I serve in the place of the Commissioner of DMR with respect to DMR's relationships with JRC. JRC will continue to accept new students, run all its programs, and serve its students under the leadership of Dr. Matthew Israel and his staff. . . . I look forward to working toward restoring a sound relationship between DMR, JRC, its students, families, and funding sources." Assisting JRC in this quest for respectability and clients, the Autism Society of America permitted JRC to exhibit and distribute literature during its 1997 annual conference held in Florida in early July.

Reprinted courtesy of The Autism National Committee

New York Times features front page story on former BRI/JRC student

TASH members Fredda Brown, Fredda Rosen, and Lisa Pitz have worked for two years with James Velez and his family to move him from BRI into his own apartment. The New York Times featured a story in a three day series chronicling James' story. Following are excerpts from the New York Times.

James Velez was only seven years old when he entered New York State's system of institutional care, and 17 in 1991 when he became a client of the Behavior Research Institute (BRI), now known as the Judge Rotenberg Center (JRC).

From his first year of life, he had suffered from a previously unknown neurological condition which caused a disturbing sensation likened to insects crawling over his body. Velez' frantic scratching left him with multiple lesions and in need of a level of care that his parents were unable to provide. Yet growing up in the Psychiatric Institute at Columbia-Presbyterian Medical Center made for a severely restricted childhood, leaving James Velez increasingly isolated and depressed. Then New York officials suggested BRI.

The story of Velez' young life, which became a three-part series in the *New York Times* on June 22-24, offered illustrations of important public policy issues raised by individuals with complex needs. James Velez' experiences in BRI's "School and treatment center" are excerpted below.

"His life became highly controlled. His daily routine was broken down into behavioral 'contracts': bed-wetting, for example, would violate a contract. When he failed to earn food, he was fed a 'loss of privilege' meal – a watery blend of chicken, mashed potatoes, and spinach. He said 'It tasted like nothing.' Slight as he was, he says he sometimes went days with not much that he liked to eat.

He also received monetary equivalents for proper behavior (and lost them if he was rude or impatient or didn't finish a meal in 15 minutes). Only with these earnings could he buy certain activities: $3 of BRI money bought a three-minute chat with another patient; $15 bought a phone call to a friend; $20 a phone call to his mother. . . .

And then there were the shocks. Five electrodes were always affixed to his skin: one on his torso, one on each arm and leg. An aide carried a radio transmitter known as the Graduated Electronic Decelerator. If James scratched or rubbed, he got a two-second jolt through one electrode. . . . Although scratching was his primary behavior problem, he was eventually shocked for 72 actions. . . .

He has often been incontinent. At night, an aide woke him every two hours to usher him to the bathroom. If he soiled his bed, he would be shocked as he slept. He would be shocked for 'tensing up' while asleep. The interrupted nights left him drowsy, but if he dozed during the day, he would be shocked.

Already suffering a low self-image, he would become embarrassed when out in public, for there he would be tethered to an aide like a bizarre human lab experiment." (*New York Times*, Metro Section, June 23, 1997, p. B4).

Finally, James Velez' state-assigned lawyer/advocate joined with his parents to remove him from BRI, despite the strenuous objections of Director Matthew Israel and BRI lawyer Michael Flammia.

After careful planning, in November 1996, a New York City agency called Job Path began serving James Velez, along with another young man, in an apartment setting with round-the-clock staff. Velez now has a part-time job, buys his own groceries, entertains his family in his own living room, and cleans (or fails to clean) his own room.

The *Times* reports that there are good days and bad days. For the most part his scratching remains in check, but not always. Keeping busy seems to be the best key to managing this perplexing problem. Institutional living has left James Velez lacking in many basic life skills, and program staff worry that the passivity and dependence induced by years of custodial care may limit his ability to take advantage of new opportunities. The Job Path agency understands that the road back will be a long one. But, as the *Times* article notes, where once there was only fear and despair, James Velez and his family now experience both hope for the future and the joys of everyday life.

Reprinted courtesy of The Autism National Committee

From the Executive Director

continued from page 5

Newt Gingrich. In a nutshell, MI CASA (H.R. 2020) amends Title XIX of the Social Security Act (Medicaid) creating a new Medicaid Service called "Qualified Community-Based Attendant Services." It allows people who would otherwise qualify for nursing home or ICF/MR (Intermediate Care Facilities for the Mentally Retarded) services to use Medicaid funds to purchase home-based services and supports. To get the bill introduced, members of ADAPT visited the office of every member of the House of Representatives to urge them to co-sponsor MI CASA. At press time the bill had fairly broad bi-partisan support and over twenty co-sponsors.

Perhaps Josie Byzek of ADAPT says it best in the recent edition of Mouth. "The birth of MI CASA is one of the most important moments in our movement. I know MI CASA's introduction hardly constitutes winning a battle. If anything, it's a declaration of war. It's also our community's Declaration of Independence. Eventually, freedom to choose to live at home, not in a nursing home, will be the law of the land. That's when Independence will mean something to the American living in a nursing home who thought he'd be dying there, too"

TASH and a number of other major disability groups have officially endorsed MI CASA. ADAPT needs other disability groups from across the country to endorse the bill. To learn more or to offer your group's endorsement, call ADAPT at 512-442-0252 or 303-333-6698, fax them at 512-442-0522, or send an e-mail to: adapt@adapt-now.com.

Before a bill can reach the floor of the House of Representatives for a vote, the subcommittee to which it was referred must hold hearings and take its own vote.

The Health & Environment Subcommittee where H.R. 2020 was referred is chaired by Representative Michael Bilirakis (R-FL). Encourage him with a letter to his office at 2240 Rayburn House Office Building, Washington, D.C. 20515. Or give his office a call at 202-225-5755. His fax number is 202-225-4085.

Other members of that subcommittee, especially if you live in their district, need your encouragement, too. You can find their names and contact information at your library.

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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SEPTEMBER 1997

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TASH Conference Registration Form

"We the People, *ALL* the People"

Sheraton Boston, December 10 - 13, 1997

Mail form to: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204-5201
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The registration application can also be found at http://www.tash.org

Registration Discounts

10% Earlybird Discount for Registrations postmarked by September 15, 1997.

10% Discount for groups of 5 or more registering together (must be mailed and received in the same envelope).

50% discount off the rate that applies (for each person) for a regular education teacher registering with a special education teacher, a paraprofessional, or related services personnel; or for any support staff person registering with a self-advocate (must be mailed and received in the same envelope).

*Only one discount in addition to the earlybird discount is allowed.

You may use this form to register for the conference only, to register for the conference and become a TASH Member or renew your membership at the same time, or to become a member only

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12 Self-Advocate
13 Support Services Provider
14 Government Personnel
15 Supported Employment
16 Psychologist
17 Early Childhood
18 Other

Please fill out this section only if you are registering for the conference:

TASH Membership: Individual Agency Membership #______________

(please note: up to three persons can register at the membership rate using an agency membership)

Student ID# (if applicable) ______________________

☐ I am becoming a member now
☐ I am renewing my membership now
☐ Please check here if you are a TASH Lifetime Member with Conference Privileges
☐ Please check here if the address above is a new address

Optional Service Information Requested (please request by November 1)

☐ Accessibility Details
☐ Sign Language Interpretor
☐ CEU Credits
☐ Child Care/Youth Activities (Note: you must fill out an application in advance to register. Space is limited)
☐ Roommate Referral Program
☐ List any accommodation needs ______________________

To Become a TASH Member or renew your Membership NOW. . .

You may also use this form to become a member at the same time you register for the TASH conference! This allows you to register for the conference at the reduced TASH member rate (see other side for member registration rates) or, *use this form to join as a member without registering for the conference.*

Membership rates are listed below. Determine the appropriate membership category, be sure to fill in the applicable rate on the reverse side of this form when entering payment information, and include payment at the time you submit your conference registration payment.

General International Membership (individuals)	$85.00
Agency/Business/University International Membership	$190.00
Self-Advocate, Parent ,Full -Time Student, Direct Support Worker, Paraprofessional, Personal Attendant, International Membership	$45.00
Family International Membership (2 people)	$130.00
Lifetime International Membership	$1,000.00

(Add $15.00 to memberships outside of the U.S. and Canada to cover additional postage costs)

Fill in appropriate membership rate on Line 4 on reverse side of this form.

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1997 TASH CONFERENCE - "WE THE PEOPLE, ALL THE PEOPLE" - DECEMBER 10-13

Registration Rates 1997 Conference	**Current or Joining International Member**	**Non-Member**	**Please Enter Applicable Cost**
General	$169	$289	
Student/Paraprofessional/Parent (Professional)	$135	$229	
Family (2 People)	$204	$420	
Self Advocate/Parent (non-professional)	$ 29	$ 39	
One Day Only Thurs or Fri	$ 99	$129	
Saturday Only Special	$ 70	$ 85	

1. Cost for Conference Registration from above .... 1. ________

- Less 10% Discount for Earlybird Registrations (must be postmarked by Sept. 15th) .... ________
- Less 10% for Group Discount or 50% for other discounts .... ________
- Please enter if applicable, see other side for details **(only one discount in addition to earlybird discount is allowed)**

Add discounts .... ________

2. Total Conference Registration Rate (Subtract discounts from line 1) .... 2. ________

Rates to add a Pre-conference Full Day TASH Tech Workshop (see descriptions, pgs. 8-9)

TASH Members	$65.00	NOTE: There is no charge for the Chapter Leadership Tash Tech.
Non-Members	$75.00	
Self advocate/Parent	$40.00	

1st Choice Tech # ______
2nd Choice Tech # ______

3. Add Cost of TASH Tech if applicable .... 3. ________

4. TASH Membership Dues Enclosed (If renewing or joining with this application, add applicable rate from other side) .... 4. ________

5. To Also Join Your State Chapter Add $15.00 .... 5. ________
(only applicable if joining or renewing TASH international membership now)

6. Yes, I will donate $5.00 to support a self-advocate to attend the conference .... 6. ________

Grand Total Enclosed (add applicable costs for lines 2-6) ________

Payment Terms

Registration will not be accepted without payment by check, official purchase order, or credit card authorization. Please note that payment must be in U.S. Funds only. A $25.00 processing fee will be deducted from cancellations received before November 15, 1997, and added to purchase orders not paid within 30 days after the conference. No refunds will be given for cancellations after November 15, 1997. After that date, registrations will be on-site only and a $35.00 processing fee will be added to all registrations. A $15.00 fee for returned checks or unauthorized charges will be assessed.

Check enclosed Purchase Order/State Voucher No. ________________

Visa Mastercard Discover Card Number ________________ Exp Date ________

Signature ________________________________

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Skill Development Products for Paraeducators, Teachers, and Parents

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LifeLines in the Classroom

Five Training Modules for Instructional Paraprofessionals Supporting Students with Disabilities in General and Special Education Classrooms

LifeLines

- Module 1 - Defining the Role of the ParaEducator
- Module 2 - Celebrating Similarities: Students with Disabilities
- Module 3 - The IEP Process: The Role of the ParaEducator
- Module 4 - Supporting the Instructional Process
- Module 5 - Behavior Improvement Strategies

Melding

A Partner Teacher's Guide to Working with ParaEducators who Support Students with Special Needs

Processes and Tools to:
- facilitate negotiation of roles and responsibilities
- foster initial and on-going communication
- promote collaborative problem solving

That result in:
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- best possible services and supports for students with special needs

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- IEP Data Collection and Reporting
- Continuum of Special Education Services
- Transition and Future Planning
- Procedural Safeguards
- Communication Strategies

Students FIRST

For more information on training topics, consultative services or other products, please contact...

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Katy, TX 77491-6049
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TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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Referred by:

Name: ____________________

Address: ____________________

City/State/Zip: ____________________

Telephone: (   ) ____________   Fax: (   ) ____________

Please Check Appropriate Categories
(not more than three):

( ) Administrator
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( ) Case Manager
( ) Day Personnel
( ) Early Childhood Services
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( ) Early Intervention Specialist
( ) Friend
( ) Gov. Personnel (Federal, State, Local)
( ) Higher Education
( ) Human Services Provider
( ) Interested Individual/Advocate
( ) Legal Administrator
( ) Library
( ) Occupational/Physical Therapist
( ) Paraprofessional/Direct Care
( ) Parent/Family Member
( ) Primary Care Provider
( ) Personal Assistant
( ) Professional Advocate
( ) Psychologist
( ) Regular Education
( ) Residential Services
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Student (College/University)
( ) Support or Related Services
( ) Supported Employment Personnel
( ) Teacher (Direct Service)
( ) Teacher Trainer
( ) Vocational Services
( ) Other

General Membership (individual) ...... $85.
Agency/business/university/college/library/school .... $190.
(allows three conference attendees)
Self Advocate, Parent, Full Time Student, Direct Careworker/Paraprofessional/Personal Attendant (for whom payment of full fee would present a hardship) .... $45.
Family (group rate) .... $130.
Lifetime Member .... $1000.

All dues are $15 higher for members outside the U.S. & Canada. Funds must be submitted in U.S. Dollars.

If you would like to charge your membership, please fill in the necessary information:
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Card Number ____________________

Expiration Date ____________________

Signature ____________________

( ) I would like to arrange to spread my payments out.
Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

How did you learn of TASH: ____________________

What, in particular, inspired you to join: ____________________

What other disability organization do you belong to: ____________________

If you are applying for a student membership, please provide the following information:

Department ____________________

College/University ____________________

Student I.D. Number ____________________

Anticipated year of completion ____________________

( ) Please check here if you would like us to send information about your local TASH Chapter.

Please make check payable to: TASH
Address: 29 W. Susquehanna Avenue
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SEPTEMBER 1997

Newsletter

AUTHORITY **SUPPORT** **RESPONSIBILITY**

CHOICES **FREEDOM**

Home of my own . . . Dreams of my own . . . Life of my own . . . Family of my own . . . Choices of my own . . . Budget of my own . . . Friends of my own . . . Future of my own . . .

Self-Determination: Reclaiming Our Lives

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WE THE PEOPLE
ALL THE PEOPLE!
TASH CONFERENCE
BOSTON 1997

Teaching Students with Significant/Multiple Disabilities in General Education Settings

Saturday December 13, 1997
Sheraton Boston

This exciting workshop is offered as a part of the international conference of **TASH** *(formerly The Association for Persons with Severe Handicaps)*. The workshop is coordinated by faculty members of colleges and universities in Massachusetts and was designed to meet the following objectives:

- to provide cutting edge information on key elements of successful inclusion of students in Massachusetts
- to provide an opportunity for practitioners to hear from practitioners from within the state
- to learn about regional inclusion exemplars
- to create regional networking opportunities

Saturday Special Conference Agenda

9:00-10:00 Opening Session
Lou Brown - University of Wisconsin-Madison
International expert on the education of students with severe disabilities

10:15-11:30 Five Concurrent sessions presented by Massachusetts school personnel and families including presentations by representatives from Boston Public Schools, Holliston Public Schools, The Federation for Children with Special Needs

11:30-1:00 A walk-about lunch (no host) with opportunities to view displays and exhibits of practices and resources

1:15-2:45 Five additional concurrent sessions presented by Massachusetts school personnel and families including presentations by representatives from Amherst Public Schools, Northhampton Public Schools, Lincoln Public Schools, Newton Public Schools, Wayland Public Schools

2:50-3:15 Closing Session

Conference Coordinators

Nancy Zollers
Boston College

Donna Lehr
Boston University

Anne Howard and **Elaine Francis**
Fitchburg State College

Sue Gurry and **Anne Larkin**
Lesley College

Liz Fleming
Simmons College

Bruce Gordon
Westfield State College

You can register for just this one day workshop or for the entire **TASH** conference. Conference details begin on page 29. Discounts are available for teams registering together. PDPs and CEUs will be available for attendance at this workshop.

For more information, please contact Denise Marshall at **TASH**
(410) 828-TASH ext 103, or Donna Lehr at
Boston University (617) 353-9310

FROM THE EXECUTIVE DIRECTOR

BY NANCY WEISS

"Self-Determination" is a term that gets tossed around a lot, but it is a term that too often is unsupported by meaningful changes in people's lives. A new national effort is underway that will put teeth into the rhetoric. Last winter, the Robert Wood Johnson Foundation, one of the nation's largest health care foundations, awarded grants totaling more than five million dollars to nineteen states. These funds are to assist people with developmental disabilities and their families to choose what supports they receive, how they live in their communities and where they find employment or other meaningful roles. Recently, additional funds were approved to assist another eight states to provide technical assistance toward systems change efforts on behalf of individuals and their families desiring self-determination opportunities. Each of these states is experimenting with ways to reverse the traditional assignment of power and build a foundation for people with disabilities and their family members to design and determine their own futures. Because we view the national self-determination initiatives as one of the most significant movements to come down the pike in recent years, we have devoted this entire issue of the *Newsletter* to the coverage of these projects.

Tom Nerney and Donald Shumway are the architects of the national self-determination movement and serve as co-directors of the national project, based in New Hampshire. "Self-Determination," as it is defined by Nerney and Shumway, means something very specific. In the past, the term has been applied loosely to everyone who is participating in a person-centered planning effort. As it is used now by projects across the country, the term "self-determination" only applies to efforts in which:

- Individuals and families control the financial resources so they can directly purchase or arrange desired and needed educational, day, or living supports;
- Individuals and families are the decision-makers in planning their own futures with assistance from family and friends as well as others whom they determine are helpful;
- Newly created or existing agencies are converted to serve as fiscal intermediaries and to provide personal brokers to support individuals and families with such services as payroll, insurance and related assistance, as needed;
- Efforts assure that managed care does not become an impersonal corporate management system but, rather, a person-directed support system. [1]

Martin Luther King said, "I have a dream." He did not say, "I have an annual plan and quarterly goals and objectives"

(Inclusion News, 1997-8).

It has been in vogue for some time to refer to people with disabilities as "consumers" but in my view, the term has always had an empty ring. One self-advocate, in explaining his dislike for the term, said that he has never felt like a consumer of services. Rather, he said, "I more often feel that I have been consumed by them."[2] People with disabilities will be consumers only when they are able to survey the range of support options, select those that suit them and, if dissatisfied, take their business elsewhere.

The Robert Wood Johnson Self-Determination Initiative will have sweeping impact on the way services for people with disabilities are allocated and controlled. For the first time, these initiatives give people with disabilities and their families the opportunity to be in the driver's seat. Rather than provider agencies "bidding" on who they want to serve, they'll be out marketing themselves — and working to make themselves marketable— so that people will choose to purchase the supports they want through the agency.

In their paper, Beyond Managed Care: Self-Determination for People with Disabilities, Tom Nerney and Donald Shumway describe four principles of self-determination. Each principle has important operational dimensions. Each state participating in the initiative is organized in different ways. For this reason, a goal of the Robert Wood Johnson initiatives is to provide a range of models for operationalizing these principles. The principles of self determination, as described by Nerney and Shumway, are:

- **Freedom:** People with disabilities will have the option of utilizing public dollars to build a life rather than to purchase a pre-determined program. Freedom means that individuals with disabilities, within some rational and cost-efficient system, will be able to control resources via individual budgets in order to gain the necessary experience in living and to move the dollars when their life choices change.

- **Authority:** Individuals with disabilities have meaningful control over a capped amount of dollars that can be used to build the supports a person needs by purchasing only what is needed and paying only for what is received. When people with developmental disabilities need assistance in controlling dollars and planning their lives, those chosen by the person with a disability to assist them in these processes should be ever mindful of the need to ascertain that individual's real desires and aspirations.

- **Support:** Support is the opposite of "programming." Assisting a person with a disability to nurture informal relationships with family and friends as part of a support network is key for those who have these natural

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TASH (The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

Building communities in which no one is segregated and everyone belongs;

Forging new alliances that embrace diversity;

Advocating for opportunities and rights;

Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

Supporting progressive legislation and litigation; and,

Promoting excellence in services.

TASH CONFERENCE

For many people who receive this *Newsletter*, this may be your first exposure to TASH. This *Newsletter* represents the beginning of several joint ventures between TASH and the Robert Wood Johnson Self-Determination Projects. We welcome our new readers and invite you to learn more about TASH. If you'd like to receive a membership information packet by mail, call us at 410-828-8274, ext. 8.

Remember, it is not too late to register for the 1997 TASH Conference to be held in Boston, December 10th through 13th. Boston is a city with an impressive history for inspiring action – a perfect match for an organization known for the same! This year's conference promises to be the biggest conference TASH has had in some time. It features almost 500 sessions – at any given time you're sure to find something going on in your areas of interest. We already have over half again as many registrants as we did at the same number of weeks out from the conference last year or the year before. We also have twice as many exhibitors as we had last year.

This is the opportunity to learn and share with the people whose combination of personal experience and professional expertise have led the disability movement. Over 2,400 advocates, self-advocates, family members, educators, disability leaders, university personnel, and community members will attend the conference. The TASH conference has always had an incredible ability to motivate and re-energize! It's one conference you won't want to miss. For more details on the conference – including a list of terrific sessions on self-determination — and registration information, see pages 29-34 of this *Newsletter*. If you'd like to receive a full agenda, call us at 410-828-8274, ext. 9 and we'll send one right out. We hope you enjoy this special edition of the *Newsletter* and we look forward to seeing you in Boston!

WHOM DO I CONTACT??

- **For issues of policy, chapter or committee support or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on the conference, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about conference registration or exhibiting call:** Rose Holsey, (410) 828-TASH, Ext. 100 or rholsey@tash.org
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- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org

FROM THE EXECUTIVE DIRECTOR

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resources in place. For those who do not, creating this informal network is important and hard work. One of the underlying assumptions of this principle is simply that ordinary community members, under more natural circumstances and environments, will welcome and support people with disabilities. It is important for us to remember that we have allowed public dollars to become an instrument of isolation and an artificial barrier between the person with a disability and the wider community.

- **Responsibility**: Like "freedom," "responsibility" is a new word in our vocabulary. Both words belong in the same sentence. People with disabilities should assume responsibility for giving back to their communities, for seeking employment whenever possible, and for developing their unique gifts and talents. For too long, individuals with disabilities have been seen and treated as dependent and incapable of being contributing members of their communities. The intense over-regulation of programs and the setting of goals and objectives to meet the needs of the human service system over the aspirations of people with disabilities, have conspired to prevent people with disabilities from truly contributing to their communities.

Nerney and Shumway go on to state that, "Self-determination is not person-centered planning, although person-centered planning is a clear prerequisite for implementing these principles. Self-determination is an attempt to fundamentally reform both financing mechanisms and basic structural aspects of the current service delivery system."[3]

People always imagine that individualized supports will cost more — but all over the U.S. experience has shown that supports that are truly individualized are likely to cost less. The way services are allocated now is analogous to the restaurant that offers only a five-course, fixed-price dinner when what you really want is only soup or dessert. When the service system catches up to current thinking and allows people not only to choose from a broad menu but to both participate in the design of the menu and control the funds, all individuals will be better served. The national self-determination initiative, along with the recently proposed MI CASA amendment to Medicaid that was discussed in this column last month, offer a real opportunity to participate in the re-thinking of the whole approach to community supports.

When it comes to disability supports, the world as we know it is changing. Though change can be unsettling, I see no greater hope for our future than people stepping forward to re-claim their own lives — and those of their institutionalized brothers and sisters. For this change to be successful, all of us — self-advocates, family members, service providers and other advocates — need to figure out how we can re-tool the roles that have become familiar to us, in support of this reclamation.

All of us have an opportunity to participate in the major policy changes that are coming down the pike. We can choose to hunker down and try to figure out ways to continue business-as-usual in the face of significant opportunities for change or we can join together, embrace the opportunity, and figure out how to leverage the changes that are coming to build communities, schools, and workplaces that include, value, engage and challenge children and adults with disabilities.

---

[1] *Shumway, Donald J. and Nerney, Thomas. (December, 1996). Pursuing self-determination. Exceptional Parent.*

[2] *Ebert, G. (1990, September). Panel presentation on "What are the meaning, characteristics and dimensions of support?" National Policy Institute on Support, sponsored by The Center on Human Policy, Syracuse University, NY.*

[3] *Nerney, Thomas and Shumway, Donald. (September, 1996). Beyond managed care: Self-determination for people with disabilities. For a copy of the complete paper contact: Martha Young, Self-Determination Project Office, Institute on Disability, 7 Leavitt Lane, Suite 101, Durham, NH 03824-3522. Telephone: 603-228-0602; Fax: 603-228-0615; e-mail: mry@hopper.unh.edu.*

HOLD THESE DATES!!

The First Annual Institute on Self-Determination and Community Life will be held July 11th and 12th, 1998!

You will not want to miss this major national conference on the most current and challenging issues in self-determination planning and implementation.

Project Directors and key participants will meet on Thursday July 10th for a day of administrative planning, sharing and discussion.

The main conference will be open to everyone who wants to attend. It will be held Friday July 11th and Saturday July 12th, 1998.

A number of cities are being considered. To assure you receive details about the conference as soon as they're available, call TASH at 410-828-8274, ext.9.

Topics will include:

- **Fiscal mechanisms that support consumer-controlled budgets**
- **Making Self-Determination a reality for people with complex needs and challenging behaviors**
- **Medicaid regulations**
- **Supporting people who don't communicate in traditional ways to design and achieve lives of their own**
- **State policy changes that facilitate self-determination**
- **Supporting people to make and maintain connections with family, friends, and the community**
- **Systems change issues for agencies that have their hearts in the right place**
- **The development of support broker systems**
- **Difficult personnel issues**
- **Supporting people whose choices challenge the system and the people who support them.... And lots more!**

MARK YOUR CALENDAR NOW! JOIN SELF-ADVOCATES, SUPPORT STAFF, FAMILY MEMBERS, AGENCY REPRESENTATIVES AND STATE AND LOCAL OFFICIALS FROM ACROSS THE COUNTRY AS THE MOST CHALLENGING ASPECTS OF MAKING SELF-DETERMINATION A REALITY ARE EXPLORED.

Self-Determination *and the* Search for Community

BY DENNIS HARKINS

> *"A new program design won't make a significant difference until the people who plan it and the people who implement it confront their own program's potential to change all the details and still leave people with disabilities excluded from the circle of membership."*
> *John O'Brien and Connie Lyle O'Brien*

For the past thirty years we have searched for community as if it were the Holy Grail. We have helped people return to the community from institutions. We have supported people to remain in their communities and prevented institutionalization. We have legalized attendance within our public schools. We have attempted to "build" community through the work of gifted community builders and connectors.

Most people with significant disabilities are now present in our communities. How many people with significant disabilities, particularly cognitive disabilities, would see themselves – or be perceived by others – as valued and active members of their communities? We have documented the many ways in which bureaucrats and professionals have created programs which have resulted in maintaining or increasing the distance between people with disabilities and other members of our communities.[1] Have we learned enough from our past to use the current thrust towards self-determination as a means for more than just an incremental increase in the number of people with significant disabilities who experience the joy of belonging within our diverse communities?

In *Members of Each Other: Perspectives on Social Support for People with Severe Disabilities*[2] John O'Brien and Connie Lyle O'Brien helped us think about what we might need to learn at the intersection of human services and natural support. In my last several years as the director of Wisconsin's state developmental disabilities services agency, I found the ideas presented in that paper to be an important benchmark against which to measure the policies and procedures I participated in creating or attempting to create. They are equally useful in discussing the opportunities and potential pitfalls of self-determination, and are an acknowledged influence on the thoughts presented in this paper.

I recently asked a group of people outside of human services what community means to them. The following response seems particularly relevant to this discussion:

Community is a state of human interaction where people can be what they are, however glorious, broken, searching, frightened, shining, whatever, and be heard and accepted by others. In a community, individuals are committed to their own and each other's spiritual growth. People have the space to communicate about what really matters to them. It's safe.

Having experienced what it is to be really heard, and having heard the deeply beautiful and powerful stories people tell when they know that it's safe for them and that they will be heard, I seek community.

If the self-determination initiative is to increase the chances for people with severe disabilities to be who they are, and to be heard and accepted by others, it will need to confront *at least* the following issues:

- the consequences of historic and continuing practices of community services which group people together, set them physically apart, isolate them socially, amplify stigma, and arouse a sense of differentness;
- the consequences of historic and continued exclusion of students with significant disabilities from regular classrooms in their neighborhood schools;
- the resultant prevalent perception that people with severe disabilities should live outside the boundary of community membership;
- laws and policies which require people to remain poor in order to receive public support;
- the fear and reality of victimization of adults with severe disabilities;
- confusion about the role of "natural support" for people who receive, or are eligible to receive, public support;

continued on page 7

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[1] As a former bureaucrat who participated in developing most of the community services practices which distance, isolate and stigmatize people with disabilities, I will spare myself the pain of reciting the long list here.

[2] Responsive Systems Associates (1990). Lithonia, Georgia.

Self-Determination and the Search for Community

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- the generally controlling nature of public bureaucracies and provider agencies; and
- the recent trend towards consolidation of developmental disabilities services through managed long term care, and/or large scale buyouts of provider agencies throughout the country by a relatively small number of profit-making corporations.

These are formidable barriers. Some are new — such as the recent decision by a few large providers that the Wall Street game of expansion and acquisition can be played within the community services sector of developmental disabilities services, as well as within the ICF/MR sector. Some are old — such as the continued need to create the conditions in which no person will reside in an institutional setting as a result of having a disability. Some are more recent, but have remained a challenge to us — such as the continued attempt to understand how to connect people to "natural support" within their communities.

Self-determination offers the promise to address these barriers in specific and concrete ways which can strengthen the place of particular individuals with disabilities within the web of their communities. It also offers the potential to become a focal point for radical, transformative change in the way in which people with significant disabilities are supported by the public system and perceived by other community members.

At the core of the self-determination initiative is the relatively simple concept of the responsible public agency allocating funds to individuals rather than contracting directly with various residential, vocational, and other service agencies. While the administrative challenges involved in making this change are not simple, they are solvable. The learning now occurring in more than half of our states through the self-determination initiatives will provide good answers to questions about the flow of money, how to set individual budgets, the use of fiscal intermediaries, ways to better utilize Medicaid dollars, and a host of other technical questions which attract smart people who spend their leisure time watching the Mars rover bore into rocks on cable TV.

At the core of the self-determination initiative is the relatively simple concept of the responsible public agency allocating funds to individuals rather than contracting directly with various residential, vocational and other service agencies.

Solving these technical issues will change the context in which people with disabilities interact with current provider agencies, with their case managers and, depending upon how the tensions with those relationships are negotiated, with other community members as well. To the extent providers must respond to the individual needs and lifestyles of each person they support, the likelihood increases that people will live in typical homes and spend their days within the "boundaries" of diversity understood and accepted by most people. In the near term, this increases the concrete opportunities for people with disabilities to join in community associations, and in the long term helps change the perception of stigma and difference which our historic service practices have reinforced.

Perhaps the greatest promise of the self-determination initiative is the potential to change the nature of the work, to shift the balance of power away from an historic system in which the economic transaction continues to primarily pay for facilities and settings that distance people from their communities.

To the extent case managers become support coordinators, brokers, or personal agents[3] working for the person, the likelihood increases that the incredible diversity in how people want to live their lives is extended to people with disabilities who receive support from public dollars. Case managers working for a public or provider agency tend now to plan and coordinate services within the constraints of existing service models. Support coordinators working for each person will have the opportunity to help people respond to the dreams and wishes which have currently become a typical component of a pre-service assessment, filed away when it conflicts with what the system has to offer. What might happen if the relatively small number of state or county contract managers who annually manage long-standing contracts with existing agencies are replaced by several hundred thousand people with disabilities who have access to that funding and have someone to help them think about how they want to live each day?

To date, most of the work which has focused on helping people with significant disabilities become valued members of their communities has been done at the periphery of the public service system. Much of that work in citizen advocacy programs, in connecting people to community associations, in community building, and in creating energetic circles of support has been painstakingly slow and dependent upon people who are perceived as being particularly gifted in the art of creating community[4] It has

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[3] Some have suggested that the Robert Wood Johnson Foundation fund a contest to come up with a term for this different function which would meet the tough criteria of being neither human services jargon, nor confused by the public with either Wall Street or Jerry Maguire.

[4] Many of those individuals would argue that they are not so gifted, and anyone can do this work who has the desire to do so. This strikes me as similar to my electrician father-in-law arguing that I ought to be able to rewire my house with no difficulty if I simply follow the diagrams.

Self-Determination and the Search for Community

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been working against the stream, against the overall set of service expectations which push people receiving services outside of the typical boundaries of community membership.

Perhaps the greatest promise of the self-determination initiative is the potential to change the nature of the work, to shift the balance of power away from an historic system in which the economic transaction continues to primarily pay for facilities and settings that distance people from their communities. The current system of paying for services requires talented "community builders" to convince other community members to ignore the messages inherent in the way in which our government chooses to spend billions of dollars. A system in which each person controls an individual budget and can begin choosing different ways to use that funding to provide needed assistance will fundamentally change that dynamic.

Such a system will allow ordinary people with disabilities, ordinary family members, and ordinary paid assistants to flow *with*, rather than against, the stream of community. It will dramatically increase the chances for people to achieve individual or cooperative home ownership, rather than live in a home owned by a group of financial investors. It will dramatically increase the chances for people to obtain different kinds of jobs and to engage in a myriad of activities each day that bring joy and increase relationships with others. It will exponentially expand the opportunities for learning from - and with - community building artists and artisans who have been helping us understand the limitations of our current policies, and the opportunities for strengthening our communities through changing current policies.

Self-determination is not a panacea for all of the current problems in our human services system and it is by no means guaranteed to succeed. It can fail mightily if it overpromises near term savings in funding or replacement of needed personal assistance by natural support. It can become an asterisk in the late twentieth century history of our field if the inherent political tensions among the many interest groups in the field are underestimated and it becomes the new lightning rod for "political correctness." It can become a new name to simply do what we have been doing, leaving so many people with disabilities as strangers to their communities.

> **Self-determination is not a panacea for all of the current problems in our human services system and it is by no means guaranteed to succeed.**

We will develop the technology to allow self-determination to flourish. We know from the stories we can currently tell that people with significant disabilities can be richly supported within the web of diverse communities. We have literally a once-in-a-millennium opportunity to capitalize on an idea whose time has come, with a moment in time which embraces change. If we approach this opportunity with wisdom, compassion and patience, we can help create the conditions in the twenty-first century in which all people with significant disabilities are able to be who they are, to be heard, and to be welcomed and accepted as valued members of their communities.

Dennis Harkins has left the community of state bureaucrats and now works with human services and community agencies through his consulting agency, A Simpler Way, 5826 Bartlett Lane, Madison, WI 53711. His e-mail address is DWHarks@aol.com.

The Southern Collaborative on Self Determination – a group of self-advocates representing People First of Alabama, People First of Georgia, and People First of Tennessee – has published:

REAL CHOICES: A CONSUMER'S GUIDE TO EDUCATING PEOPLE ABOUT SELF - DETERMINATION

REAL CHOICES is a training kit that includes information on:

- What is the Self-Advocacy Movement?
- What is Self-Determination?
- What is the Robert Wood Johnson Self-Determination Project?
- Making Our Dreams Happen: Principles of and Steps to Achieving Self-Determination.
- Activity Page: Dream Catcher.
- Life Today and Tomorrow: Before and After Self Determination.
- How Can You Help?
- Transparencies for each page are included.

The presentation kit is designed to assist self-advocates and others to help people understand what self-determination is all about and why it is so important. The kit discusses common barriers to achieving self-determination and what self-advocates and others can do to overcome those barriers.

To order a presentation kit, send your request, along with a check or money order for $30 for each book ordered (includes postage and handling) to:

People First of Tennessee, Inc.
855 W. College Street, Unit D
Murfreesboro, TN 37129

For more information, call People First of Tennessee at (615)898-0075.

Self-Determination: Transferring Agency Control By Re-Thinking Its Role

BY JAMES DEHEM AND LISA CHAPMAN

In Hollywood, a caped crusader will swoop down and stop an out of control speeding locomotive. In real life, solutions aren't as easy. However, one agency in southeast Michigan is looking to slow down and reverse a large powerful system of housing and services for people with developmental disabilities. The hero-like figure in this scenario just might be a concept that is gaining momentum nationally and is known as self-determination.

Re-shaping its current system of providing supports for people is the goal of Wayne Community Living Services, Inc. (WCLS), a large non-profit corporation in the metropolitan Detroit area. WCLS is a major project site of Michigan's Self-Determination Project supported by the Robert Wood Johnson Foundation. WCLS is a giant in the industry in that it serves 1,700 people with developmental disabilities in housing, employment and other supportive services with a $123 million budget. The agency's dream is to transfer its well-oiled system of group homes and other "residential" programs to a more personal way of supporting people in pursuit of their dreams without formal models of service. Self-determination is viewed as the significant philosophical foundation for this transition.

The Self-Determination Initiative is built on the principles of freedom, authority, support and responsibility in pursuing a life of one's choice (Nerney, Crowley, 1995; Nerney, Shumway, 1996). The components include a reasonable, individual budget, the authority to control that budget, a network of supports, and the responsibility that a person accepts in engagement with the community.

Guided by this movement's focus of transferring control and authority, WCLS is overhauling its entire system. Through person-centered planning, control is shifting as inter-disciplinary teams are being replaced by support circles, driven by the person with a disability, and assisted by those he or she requests to be involved. The authority also is being shifted directly to the person as he/she controls his/her own resources, chooses both supports and providers, and finally evaluates the whole process.

From Where It Came

The state of Michigan formed WCLS as part of its efforts to close three institutions in the county of Wayne. This part of Michigan includes the city of Detroit and is essentially a major urban area of over three million people. WCLS was created with the mission of "placing" persons out of "developmental" centers in accordance with Michigan's plan for deinstitutionalization. A major factor influencing that plan was the Plymouth Consent Decree, the result of a nationally significant lawsuit that forced the closure of the Plymouth Center for Human Development, which at one time had a census of over 1,200 people with disabilities.

At that time, Michigan gained a national reputation for a massive systemic approach to closing its thirteen state institutions for persons with developmental disabilities primarily through the use of a six-person group home model. In the heyday of that initiative, WCLS would develop between 25–35 group homes per year, including six-person Intermediate Care Facilities (ICFs/MR), to provide barrier-free alternatives for those who had been in nursing homes and health care units.

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Transferring Agency Control

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The ICF/MR program was seen as a tremendous boost to the state's economy and an impetus to the notion that people with significant needs could leave the institutions. Masses of people were liberated from the institutions and now are living back in their original communities.

Soon it became apparent that the six-person home model was not the ultimate solution. People wanted fewer housemates. They wanted freedom from the structure of a group home and, in particular, from the controlled rigidity of life in an ICF/MR home. The standards for the ICF/MR were controlling WCLS and in turn, controlling people's lives. In order to remain certified for Medicaid funding, teams planned how a person's day would be lived. The focus became a clinical treatment milieu rather than what people and those close to them wanted in life.

Steps to System Change

Self-Determination represents a fundamental shift in not only how WCLS views itself as an agency, but also in how an entire organization is funded and operates.

That shift takes several forms in the agency's self-perception and the ways in which the organization supports people:

- **from a service system, to a provider of supports;**
- **from placing people into segregated group housing, to assisting them to live where and with whom they want;**
- **from team planning for people, to individuals being assisted by those they trust in identifying how they can achieve their own personal dreams;**
- **from an agency that determines how it will spend its financial resources to serve people, to an agency that puts money and other available resources in the control of the individuals themselves;**
- **from an agency that sets its values and evaluates its performance on process and professional standards, to one that focuses its mission, and measures its success, on the satisfaction of the people for whom it exists;**
- **from a position of power and control, to one that empowers and transfers authority to people with disabilities and their families by shifting the control of its resources to them.**

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...the first and most critical step is for leadership to view self-determination as a change for the better and not an indictment of either present or past systems or the people associated with them.

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Needless to say, these concepts are significantly different, not only from the way WCLS has operated in the past but also from the way most agencies in the country operate. For many, these concepts are also against the grain. Losing control – much less giving it away – is every administrator's nightmare.

In a similar way that the deinstitutionalization process generated a hesitancy to vacate buildings at state hospitals, a similar resistance can now be felt toward abandoning the systems that were originally designed to eliminate the institutions. For many, to say that what we once did needs to change implies that what was done was wrong. That's often a tough admission for those who have personally invested so much of themselves or now view their futures in jeopardy. Nonetheless, the first and most critical step is for leadership to view self-determination as a change for the better and not an indictment of either present or past systems or the people associated with them.

Another major adjustment WCLS has had to make is with its staff who historically developed homes, case managed and provided clinical services to people. Staff who "developed homes" now are assisting people in finding housing. Staff who provided assessments and intervention now do so only if requested by the person with a disability.

Perhaps the most crucial change needed in WCLS' system is its participation with Medicaid. As it currently exits, WCLS receives a majority of its funding from participation in the ICF/MR, Community-Based Waiver and Clinic Services Programs in Michigan's plan. System requirements and billing structure pose significant challenges to funding individual dreams because these typically are fashioned around an eligible service model. Efforts are underway, however, to restructure the state's plan by means of a capitated single funding stream.

A Model of Community Service

The transition to a support model from a service model requires re-thinking how individual needs for resources are filled. WCLS historically has funded most everything in a person's life, from food, clothing and furniture, to staff, therapy

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and specialized equipment. Similarly, virtually everyone who has been involved with a person has been a paid staff person. In the support model, WCLS is looking to collaborate with the person and his/her circle to utilize generic resources and in-kind or trade-off supports. As citizens of their communities, people with disabilities are eligible for many sources of support that are available to anyone. Those resources that relate to low income such as food stamps, housing vouchers and public utility programs can be used to offset costs so that agency budgets can be better utilized to fund supports specifically related to disabilities.

Connecting people to family and friends is fundamentally right. We all know the intrinsic value of caring, loving people in our lives. By connecting people, however, we also gain in-kind supports. If family or friends could replace paid staff for the equivalent of one eight hour shift per week, the amount of money that could be redirected to other needs would be $7 million per year in an agency the size of WCLS. Think of the value, both in human and financial terms, of replacing group homes with shared housing with family and friends.

The Support Coordinator

At WCLS, "case managers" are now "support coordinators." Their job has changed significantly. Their job is now brokering supports rather than simply overseeing and managing services. This is a key component of self-determination. The role requires a relatively different skill set whereby support coordinators are more like agents of the person with a disability – connecting him or her with community resources and generally assisting in carrying out the plan for reaching his or her dreams in life. People can choose or replace their support coordinator at this point and WCLS is exploring how to support individuals to select a support coordinator from outside the agency.

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The transition to a support model from a service model requires re-thinking how individual needs for resources are filled.

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The Fiscal Intermediary

A key element to spending a personal budget is a fiscal intermediary. The role of the fiscal intermediary is to pay bills for the supports an individual receives. A fiscal intermediary is necessary because of the present situation that prohibits Medicaid dollars from going out as cash payments. Further, it saves the person from the tremendous legal responsibility involved with paying staff. Based upon the authority of the person with a disability, checks are written by the fiscal intermediary for supports covered in the budget and provided to the person.

WCLS had developed fiscal intermediaries several years back as part of a "Home of My Own" grant project. Local Arc's have provided this service for a nominal administrative fee. A contract exists between WCLS and the Arc and another is written between the Arc and the person with a disability. The Arc, for example, would pay the wages and handle related taxes and withholdings but would not be the employer. The employer is the person with the power to locate, hire and if needed, fire staff.

For people who have significant staff needs or when someone does not want to be an employer, current home providers are being utilized as personnel agents, much like a temporary staffing agency. This re-defines their role from a group home operator and maintains their expertise in recruiting and managing direct support staff. The person with a disability is still able to select or replace staff or, if not satisfied, select a new staffing agency.

Where It's All Headed

As a large but typical bureaucratic organization, WCLS is embarking on a journey toward systems change which will not occur overnight. It is anticipated that transferring authority and control to the very people WCLS is charged to assist will result in a truly accountable, efficient and effective way to support them. Although this story is just being written, there will be no real super hero to save the day in the end. There will only be many creative stories along the way which will form each chapter one by one.

James Dehem is the Executive Director of Wayne Community Living Services, Incorporated. Lisa Chapman is the WCLS Project Coordinator for the Robert Wood Johnson Foundation grant for Self-Determination. Wayne Community Living Services, Inc. is under contract with the Detroit Wayne County Community Mental Health Agency.

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SELF-DETERMINATION —
A FAMILY PERSPECTIVE

BY CAMERON TEASE

With Sean in his living room: (l-r) Pat Woodruff, coordinator; Sheila Mahon, case manager, Sean, with Sasha on his lap; Brandie and Eric, caregivers; and Marie Magee, Sean's mother.

Our son Sean was 17 when he was involved in an unthinkable automobile accident that resulted in his being severely disabled from a traumatic brain injury. That was over eight years ago and in looking back at those years there are two distinct chapters. I would like to share with you some details about the second chapter, which deals with Sean being in his own home now for two and a half years after five years in a rehabilitation center.

When the accident occurred on August 25, 1989, Sean was a high school student enjoying the summer before his senior year. His interests included basketball and being with his friends. He was looking forward to his senior year and being on the basketball team at Keene High School, which is located in southwestern New Hampshire. His traumatic brain injury resulted in severe disability which continues to necessitate 24-hour care and total assistance.

Sean is fed through a J-tube, and has a variety of medical challenges. During the first five years, he lived at a rehabilitation center in Boston, nearly two hours away from his mother and me. We usually were able to see him only on weekends and were constantly frustrated by a lack of first-hand knowledge of how he was doing. In addition, he was contending with a variety of medical issues such as recurring pneumonia and decubitis.

As the years went by after Sean's accident, we became increasingly determined that Sean needed to be at home. We perceived a lack of supervision and consistency in Sean's care and constantly thought about Sean lying in bed or being placed in a wheelchair in front of a TV for hours on end without being with his family and friends. We explored a number of options, closer to home such as rehabilitation centers, nursing homes, and residential homes. None seemed to meet his needs and some of them felt Sean's level of care was beyond the scope of their programs. As his mother and I are divorced, we also struggled with how to care for him at home.

As we searched for an answer, we started meeting with Monadnock Developmental Services, our area agency in southwestern New Hampshire, handling programs for people with developmental disabilities or head injuries. The idea of having Sean in his own home was broached. At one time this had seemed impossible to imagine because of the complexity of his care, funding, and the organizational and logistical issues. We were fortunate to become part of the Self-Determination Project. This project was funded in part by the Robert Wood Johnson Foundation and Monadnock Developmental Services was on the cutting edge in terms of participation in the project. We put together a budget that provided for Sean being in his own apartment, in his home town with 24-hour care. His mother and I would be co-managers of the program with support from Monadnock Developmental Services. One of the happiest days I can remember was when we learned that our budget had been approved and that we could actually bring Sean home. The adaptations to his apartment were still being completed when he arrived home in March 1995. We had hired staff, most of whom were inexperienced, however their hearts and minds were open to

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Self-Determination - A Family Perspective

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helping someone and being part of a team that could make a real difference in someone's life and that of their family.

Since Sean moved into his apartment two and a half years ago, we have gained experience, confidence, and fervor about self-determination. Even with his severe disabilities, the quality of Sean's life is so much better. We see him daily, and can drop by from work during lunch. He has seven to eight caregivers, three of whom are full time. Most are young people, both men and women. They receive caregiver training, medication training, and ongoing support through our staff meetings, and educational endeavors. The diversity of people in the program working with Sean has enriched all of our lives and it is great to see how some of the young caregivers have used their experience with Sean to move on with a new found sense of self-esteem and direction. Sean is out in the community constantly, whether it is going to the movies, going for a walk around his neighborhood, or going to sports events. His home is a bright first floor apartment that he shares with his cat, Sasha. It is clear what self-determination and living in his own home mean to Sean: improved quality of care, a team approach to working with him, and caregivers who actually become friends and stay in touch even after they have left. And smiles. After five years of rarely seeing a smile, they are now regular occurrences on Sean's face. Most of all, he is treated with respect.

One advantage to having Sean home that we never anticipated was that once people get to know him in his neighborhood, or friends of the young people who work with him have met him, there is a snowball effect. People stop over to visit, volunteer to work with Sean, and ask for the opportunity for employment. As parents, we are much freer and able to work on quality things with Sean rather than worrying and feeling guilty for the lack of any control in his life. There is a much more holistic approach by the medical community who know Sean and know that they are going to have him as a regular patient. Holidays and gatherings are often at Sean's home. In short, self-determination for our family has been the next best thing to the miracle of having Sean the way he was before his accident.

Sean out for a walk with caregiver James Desmaris

We still live one day at a time, and continue to deal with the many issues of care that come along with such a severe disability. Sean is involved in all decisions, and clearly expresses his will through his hand motions and facial expressions. He is treated with respect and as a person. People have the time and the inclination to get to know him. Surprisingly, many of his best friends are people that he has met since his accident.

Self-determination has allowed us as parents to be proud of Sean's spirit and determination, to work to make the program even more efficient, and hopefully to serve as a model to others with severe disabilities to show that it can be done. From a cost standpoint it is significant that our program is actually costing less than the institution, partially because of the opportunity for family, friends, and volunteers to be part of the program. We have all been empowered by self-determination, and we have a sense of pride at being able to live life to the best of our abilities.

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A Visit with Sean and His Team

BY ELLEN CUMMINGS

As my door opened in front of Sean's house, the smell of crisp autumn met me. I knocked on the kitchen door, eager to observe a staff meeting and learn more about Sean. I was greeted warmly by Sean's dad. From inside, there was the sound of laughter and chatter. The smell of home cooking filled the air. "Home," I thought.

In the living room, a group of lively young people were sitting with Sean, his mom, and the nurse who coordinates his services. Sean was lying, slightly propped from the waist up, on a mobile bed … supported by pillows and a handmade quilt; he was napping. His mom sat next to him, her hand stroking his arm. The intensity of her feelings showed in her eyes.

Sean's dad pulled in a chair to make a circle, introduced me to everyone, and with that, the meeting began. First on the agenda – Sean has been pneumonia free for an entire year! Cheers, applause and laughter. Then a discussion of new issues … such as the decreased tone Sean is experiencing and how it is limiting his treks into the outside world since he cannot sit in his wheelchair any longer. Different members of the group offered information – one surfed the net and found two new experts. One tried calling hot lines. Sean will be going to a new neurologist.

Mom talked about the new checklist she is designing for staff. One member of the staff suggested they keep a log of what works and what doesn't; also of what needs to be learned. A friend will put the log on the computer.

Every aspect, every detail is openly discussed; every problem collaboratively solved. Dad indicates that the budget is tight and raises may not be possible. Then some great news – Sean's grandparents are coming! Sean's eyes open briefly. He makes a strong sound with his rich baritone voice. Everyone is silent for a few moments. I see tears in some eyes.

Sean giving gifts to caregivers Christine MacDonald (left) and Dana Greisbach upon their graduation from college.

On to more business. A young man interrupts … "He's not comfortable. Maybe we should try the pillow sideways." All attention is focused on Sean until everyone is assured that he is comfortable. The discussion shifts to staff changes. One person is going on maternity leave, another is leaving to begin student teaching.

Sean's dad announced that visitors from Japan would be coming to see Sean the following week. "They want to see how people who need a lot of help are treated here. Maybe it will help other people to be treated better." "Did you hear that, Sean," says his mom, again stroking Sean's arm, "You're going to help a lot of other people." Sean's eyes open. The sound he makes is deep and rich.

A thoughtful young man who is relatively new to Sean's staff indicates that he has something to discuss. He feels that the movement classes Sean has been going to are not right for him. "He had this 'Leave me alone' look most of the time and I knew he was uncomfortable there … he was very polite to everyone … it's just that he's a 24 year old man like me and I don't think it's for him." As this new discussion ensues, I suddenly realize that I am privy to something so beautiful that tears well in my eyes. These people have never worked in the system. They've never learned about limitations. They look at Sean and see Sean. They envision nothing less for him than they do for themselves.

Self-Advocates Discuss What Self-Determination Has Meant To Them

> ***"Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has."***
>
> **Margaret Mead**

It is a Wednesday evening in late September. ***"The Lively Lifelines Integrated Training Group"*** is meeting at a Friendly's Restaurant in Keene, New Hampshire to discuss one of their favorite topics, Self-Determination. The group is made up of four individuals labeled with disabilities: Mary Starkweather, Scott Stone, Mary LeClair, Cheryl McDonald, as well as Art Hawley, Mary's Starkweather's partner, and two facilitators, Susan Morisson and Richard Reho. They are all recent graduates of a series of classes led by Morisson, Reho and Gail Dupre, entitled ***"Tools for Self-Determination."*** All of the members of this group are living lives they've designed themselves and are controlling their own budgets. Although there were 15 students who completed this course, these four individuals decided that they wanted to continue with the learning process and work toward expanding into a training group.

- Mary Starkweather (MS), who suffered a traumatic brain injury from a car accident, describes herself as a spontaneous "ageless" woman with an everlasting sense of humor. She enjoys life despite being in a wheelchair, and is committed to helping others, as well as herself, to get what they need in life.

- Mary LeClair (ML) describes herself as an outgoing 21-year old woman who loves being with animals and in nature. She enjoys studying about natural healing and knows a great deal about herbs. She will be taking a massage course this Fall to complement her native skills in massage.

- Scott Stone (SS) tells the group he is an honest, trustworthy person. He has already achieved some of his goals, such as getting a car and working fewer hours at night so he can socialize more.

- Cheryl McDonald (CM), who has Spina bifida and uses a wheelchair, feels she is patient and responsible. Her greatest challenge thus far is to find a boyfriend who will respect her and be understanding of her challenges.

- Art Hawley is Mary S.'s partner and best friend. They met when Mary was in a rehabilitation center and have lived together for several years. They are currently purchasing their own home through the *Home of Your Own Program*. Art is non-disabled.

To communicate the group's feelings about self-determination, they decided to use a question and answer format. The questions were asked by the two facilitators. The answers are given in the exact words of the participants.

• *What Is Self-Determination?*

MS: Self-determination is about the choices I get to make about my life and how I want to live it.

ML: It's about being able to have your dreams come true for real.

SS: To me, it's really about being able to have peace.

CM: Self-determination is about learning to make your own decisions and about doing things on your own without others making decisions for me.

• *So, Does Self-Determination Mean More Than Simply Getting What You Want?*

All: Yes, definitely. It also means getting to know who you are and then taking responsibility for who you are.

MS: It means standing up for others who can't speak up for themselves, too.

• *Then, Does Self-Determination Mean Being Responsible To Your Dreams As Well ?*

MS: Yes, we must be responsible to ourselves — to who you are and to your dreams.

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Self-Advocates Discuss What Self-Determination Has Meant To Them

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SS: I learned that I must be responsible to myself before I can be responsible to others or before expecting them to be responsible to me.

• *What Have You Found To Be The Best Way To Learn About Yourself?*

MS: The classes helped a lot. We learned the importance of being aware of others as well as of ourselves. It's another way to get to know yourself, since as human beings we are a lot alike and have many of the same feelings, fears and dreams.

ML: It helped to listen to what others said about me and seeing where I was compared to other people. As I spoke up and others shared their feelings, I learned a lot about me and them.

MS: We learned how to make friends and trust them. We learned by their showing us parts of ourselves, themselves and the world beyond how we've known it.

CM: I don't learn by being told what to do. Never have and never will. This only makes me frustrated, angry and embarrassed. I won't become an adult by being treated like a child.

ML: When they (the system) take charge, I have no part in things - no power and no space to be.

• *How Can You Be Responsible To Your Dreams?*

ML: It starts with defining your dream and then working at it. You have to look at your inner self and get to know why you're in the world. You need to get to know who you are and where you want to go.

CM: Once your dream is defined then you can go for it.

ML: It's also important to let others know what your dream is so they can support you to get it. It's hard to do alone.

MS: That means you need to find people you can trust with your dream.

• *So, It Sounds Like Developing Real Relationships With People Is Important. How Can You Do This?*

ML: To have a real relationship you need to be willing to share, to communicate honestly and to respect others.
CM: Being a good listener is important.

SS: Take an interest in others. Take the initiative in making friends.

> *"I want to live in a world where people see me as I am, a whole person, rather than just seeing my disability."*

AH: Get along with others and find a common ground to work from, especially if there are a lot of differences.

• *How Do You Earn The Respect Of Others?*

MS: Respect others and they will respect you. This has been hard for me to do because there are so many untrustworthy people out there. The class was a safe place to learn the skills I need to do this.

ML: Respect the space and privacy of others and they might do the same.

AH: I think if you keep your own commitments you have a better chance of being trusted - what you want you have to give first.

• *Are We Responsible To Help Others Build Their Dreams?*

MS: Self-determination is really standing for what's right — for everyone not just yourself.

• *How Has Self-Determination Changed Your Life?*

MS: I got to live with my boyfriend in my own home. I really loved the house, but everyone said it wasn't right for me. I didn't give up and kept advocating for what I wanted. It took breaking a lot of rules, but the system was willing to bend a little for me and modify the house so it did meet my needs. I know that I will stand up for the right of others like myself to have their heart's desire, too. I will teach others how to go through the process of getting your own home and to not give up when others say it's impossible.

ML: I got to know me better — I'm much happier. I got to live with a family on a farm with the animals I love and be close to nature. These are the things I learned were important to my happiness. I also got the courage to let the staff go who weren't really helping me anymore and to hire those who would support me in achieving more of my dreams.
SS: I changed my work situation so I have more time to have a life. I overcame my terrible shyness and began having more fun. I also learned how to end a bad relationship that was hurting me.

CM: I got off a medication that I was on for over 20 years because all it did was make me tired and grumpy. I chose to move into a different house with a new supportive roommate — and I got my first boyfriend ever.

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Self-Advocates Discuss What Self-Determination Has Meant To Them

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• *Can You Share More About How Your Life Is Different Since You Became A Self-Advocate Through The Class And Other Experiences?*

MS: My life has changed completely. It has moved from being incomplete to being complete. Before I didn't know what I could or couldn't do. Through the class, I became more aware of myself, as well as others.

CM: I am now able to make decisions without someone making them for me, which is what happened in the past. As a result of being able to make my own decisions about my life, I am more cheerful. My confidence and courage are growing with each step I take on my own. I have also become more patient with myself. I am able to deal with situations more positively and without as much anger and frustration.

SS: I have been able to start making my dreams come true — like getting a car and beginning to meet new people. Before the class, my life was awful. I was always alone and lonely. Now I am beginning to have a social life because I have improved my social skills a lot. I am also having a better quality of relationship with people — my friendships are deeper. Now that I have overcome my shyness and learned how to communicate more, there are more things that I can do. I even got to go to Washington and to speak to a lot of important people about disabilities.

ML: I was shy and scared all of the time. I had no one in my life to talk to or to trust. I was always being told what to do because I couldn't make decisions and wasn't able to speak up for myself. Now, I am getting better at making decisions for myself – like the first big decision I made about where I wanted to live. I find that I get stronger with each decision that I make, and no longer feel bad or guilty about my decisions, even when they affect others.

> *"It has taken a long time to build the self-esteem and find the power within to keep advocating for the life I want and for the lives of others in the same position."*

• *In Order To Get To Where You Are In Life, What Was Your Greatest Struggle?*

ML: My greatest struggle has been with the system itself. I was treated like a child until I learned to identify my own needs and to speak up for myself. I had to learn that I could stand up for my own beliefs and then get the strength and courage to do it — the class supported me in this.

MS: My greatest struggle was also with the system. The State wanted me to stay institutionalized after my car accident. I didn't want to spend my life that way and have been fighting for myself ever since. It has taken a long time to build the self-esteem and find the power within to keep advocating for the life I want and for the lives of others in the same position as me with the system. I am learning how to deal with my anger and guilt in positive ways.

• *Now That You Feel That You Are Beginning To Direct The Course Of Your Lives And Growing In Confidence, What Are Your Goals and Dreams?*

SS: I want to start working on building a life that is not so lonely and isolated. I want to be part of a situation where people like me and care about me and want to do things with me.

ML: I want to live in a world where people see me as I am, a whole person, rather than just seeing my disability. I have faced so much prejudice in my life, especially in employment. I want to work so much, especially with animals, but I'm always being judged.

Everyone grows silent and thoughtful. They have said a great deal, but all seem to realize, in this short moment of silence, how much more still remains to understand and say – and more importantly, to take responsibility for and act upon.

"The Lively Lifelines Integrated Training Group " is available for presentations and trainings on Self-Determination. For more information, please write or call:

RICHARD REHO
38 Gilsum Street
Keene, NH 03431
(603) 355-1012

ONE STATE'S SELF-DETERMINATION INITIATIVE

Maryland's Self-Determination Initiative

BY SUZI BURKE HARRISON, JOANNA PIERSON, AND DIANE COUGHLIN

Over the past decade the Maryland Developmental Disabilities Administration, (DDA) has been moving toward designing and delivering services and supports to people with developmental disabilities in a more person-centered way. Moving from "slot-based" programs to individualized supports and services has been a process that has forced the service delivery system to become more flexible.

Major changes were seen once funding for individuals was no longer artificially "attached" to a program but became that individual's money. That change provided opportunities for people to take their public dollars and pay for requested supports and services from any DDA licensed provider. For the first time Marylanders with developmental disabilities were given some control over their lives. Along with that effort, person-centered planning became part of the best practices in Maryland. Discovering each person's wants, needs, and wishes became a critical part of designing services for people with developmental disabilities. When Maryland was awarded a Health Care Financing Administration (HCFA) grant to implement Community Supported Living Arrangements, further changes in service delivery were seen. Recently, the Great Oaks Center in Silver Spring, Maryland, a state-funded facility, was closed using a person-centered planning process. Individualized plans were designed and implemented for over 200 people who now live successfully in various communities throughout Maryland.

While significant changes were already being made in how people with developmental disabilities received services in Maryland, it was clear that further and more sweeping changes were needed. The threat of a managed care system that was poorly designed and ill-prepared to address the complex needs of many people who have developmental disabilities increased both Maryland's sense of urgency and the commitment of the Administration to address this in a well-thought out, person-centered way.

Last winter it was announced that Maryland had been selected by the Robert Wood Johnson Foundation to receive a $400,000 grant to implement the much needed systems change. The grant proposal, which was written in partnership with the Developmental Disabilities Administration, The Arc of Frederick County, and the Developmental Disabilities Council, outlines changes in how the service delivery system is organized, managed, and financed.

Maryland proposes to accomplish this by developing a series of local, non-profit resource coordination agencies which will empower users of services while making the best use of scarce public resources. Efforts will begin with the development of two local resource coordination agencies by transforming The Arc of Frederick County, currently the largest provider of independent services coordination in Maryland. Each person in the target areas will receive support brokerage which will seek to implement those services and supports that have been identified in the person-centered plan. Individual budgets will be developed with the resource coordinator, the person with the disability and other key stakeholders. It is intended that community supports will be used as much as possible when developing and

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The project has begun in four of Maryland's twenty-four counties but the **changes are expected** to be implemented state-wide during the next three to five years. **The proposed** changes will fundamentally change the way that services are structured by:

- Giving people with disabilities (and their families) substantially more control over the services they receive and how they are provided;
- Reducing the average costs of current services and passing the savings on to Marylanders with developmental disabilities who are waiting for services;
- Creating a series of partnerships (building on those that are currently present) between people with disabilities and their families, service providers, advocates, state and local governments, and Maryland's communities;
- Seeking an equitable balance between the needs and desires of those people currently receiving services and the needs and desires of those waiting for services; and
- Supporting people with developmental disabilities in their communities in lives that they have chosen.

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Maryland's Self-Determination Initiative

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implementing each person-centered plan.

The resource coordinator, as a support broker, will be given the authority to help people with disabilities to purchase the exact supports and services that they want, along with connecting people with their communities. They will be responsible for spending the money wisely and creatively to help create a savings that will enable people who are currently on DDA's waiting list to receive services.

The strong leadership and commitment to change from the Developmental Disabilities Administration, the revisions of regulations, policies, and the payment system help to create an excellent climate for systems change.

Tim and Sue: A Struggle for a Life Together

Tim and Sue* had one thing that they wanted above anything else. It wasn't an outrageous request. In fact, many of us are doing or have done the very thing that they wanted to do. What is the major difference between their simple request and one that "we" might make? Both Tim and Sue receive public funds from Maryland's Developmental Disabilities Administration which makes them part of "the system."

What they wanted more than anything else was to share their lives together and live together. They had been telling anyone who would listen but most people were not listening. So they took matters into their own hands. Instead of working at community-based jobs, which they clearly could do, they stayed at "the center" so they could be together. They also figured out if they got admitted to the psychiatric unit at the local hospital, they could be together. Clearly they were getting desperate.

To make things a little more complicated, Tim and Sue got residential services from two different agencies. Under the new self-determination initiative, Tim and Sue's resource coordinators worked together with the providers so that today Tim and Sue share an apartment and a life together. By using their resources, funds and community connections wisely, the resource coordinators were able to build in the supports that this couple needs for less than Sue's residential services had cost alone. The services and supports were unbundled so that only those things that Tim and Sue want are being paid for. The savings will be used in two ways. First, a small "risk" pool will be created for future services that Tim and or Sue might need. The rest of the savings, which is almost the entire cost of Tim's previous residential services, will be used to fund supports and services for someone from that county who currently receives no DDA funded services.

With the principles of self-determination as a guide, the resource coordinators were able to help Tim and Sue have the life that they wanted.

*Names have been changed.

Suzi Burke Harrison is the Project Director for the Robert Wood Johnson Foundation Project in Maryland. Joanna Pierson is the Executive Director of the Arc of Frederick County. Diane Coughlin is the Director of Maryland's Developmental Disabilities Administration. For more information about the Robert Wood Johnson Foundation Project in Maryland, contact Suzi Burke Harrison at (301) 663-0909.

COORDINATOR OF CONSULTATIVE SUPPORT

Developmental Resources Corporation (DRC), based in Raritan, New Jersey, is seeking a Coordinator of Consultative Support. Responsibilities include the development and implementation of all agency staff training curriculum and the supervision of and leadership to a group of Community Support Consultants.

DRC's nearly 200 direct support employees provide individualized supports in various living and employment situations using positive support strategies. Our partnership with people who have disabilities is dedicated to a mutual process of creating individualized, positive change toward the realization of personal growth, development of new skills, dignity and respect in relationships, self-determination, and the exercise of personal choice.

Bachelor's degree in a related field and two years of experience in providing community-based supports, including two years in a supervisory capacity. Appropriate additional experience may be substituted for the required education. Knowledge of various idealogies, and experience in presenting information, training, and facilitating discussion in a large group setting required. Salary in $30,000 range is negotiable based on education and experience.

Fax resume to Patty Kowalchuk, DRC, (908) 707-1814/(908) 526-7960 or send to 1130 Route 202 South, Raritan, NJ 08869.

— NEW LIFETIME MEMBERS —

TASH extends its heartfelt welcome and thanks to the following new lifetime members:

Laura V. Glomb, Mark Partin, Dianna Williams and Chyong-Hwa Yeh

The Journey Toward Self Determination: TWO PEOPLE'S STORIES

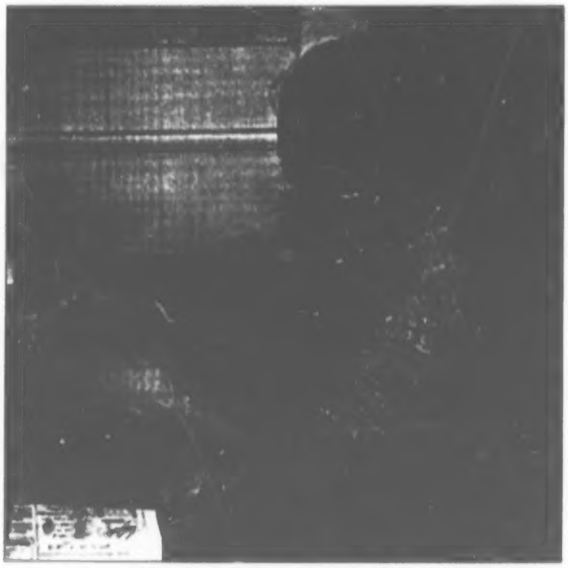
BY ELLEN M. CUMMINGS

There is a movement spreading among people who have disabilities. It is the movement toward self-determination—toward controlling how their lives will be lived and to have authority over the resources needed to support them in making change happen.

BECKY'S STORY

When Becky opened the door to her apartment, I was startled by a powerful strobe light flashing in front of me and I began to see spots like one does when a camera flashes. I soon realized that it was the silent alarm that signals Becky that her phone is ringing, her door is opening, or a fire is smoldering. The kettle was on and Becky smiled as I entered, holding up two canisters—one with coffee and one with tea. I, like Becky, chose tea. We then walked over to the kitchen table where Becky had been playing cards with her support person and confidant, Anna. Trying to conduct an interview was very difficult because I was neither able to sign nor interpret, and Becky was neither able to hear nor speak. Anna offered to be a go-between and the conversation began.

Anna talked briefly about the past. Becky had lived in a group home with roommates she had not chosen. Everyone believed that she needed to be supervised 24-hours a day and could never be by herself. "She showed everybody they were wrong." Staff were not required to learn or use sign at the group home where Becky used to live even though two residents of the house were deaf. It was believed, according to Anna, that neither Becky nor the other individual would be able to learn sufficient sign, so communication was not considered a priority. The house in which Becky and the others lived never developed into a home and Becky's response was to continually run away. When the group home residents began planning their lives independent of one another, Becky was clear that she wanted her own apartment. An apartment was found and a paid roommate moved in with her. Again, Becky ran away. By this time, her team had been replaced by a circle of friends and relatives. They made the commitment to learn and use sign and they realized what Becky had been saying for so many years through her running away: that she wanted a life of her own, in an apartment of her own. No roommate, except for her cat. They promised to be there for her if she stumbled when unwise choices were made. They help her work through the decision-making process and to learn, as we all do, that the greatest lessons in life often come from our mistakes.



Becky works on her Halloween decorations

Becky loves her apartment and her freedom, her family and her friends. She has a busy social calendar. She dates and has friends over for dinner, she is an avid sportswoman, she volunteers with young children at a local school, she is expanding her use of sign and has taught sign classes, and she has hosted a silent dinner at a downtown restaurant. She has, with the support of those who love her, created her own life, which she lives with unbounded energy and optimism, trial and error and lessons learned.

Once under watchful eyes 24 hours a day - except when she was able to run away - Becky now has a flexible staffing line in her individual budget. She can call Anna in when she needs some help - up to an average of 40 hours a week. If she only needs help 25 hours in one week, that is what she gets. If she becomes ill and needs more help, she can use more paid time. Each day's schedule is flexible and lived at whatever pace Becky decides. It is her responsibility, and that of her circle, to stay within her budget. Once considered unable to care for herself, Becky is living a life of her own making. She has a job and a bank account. With help from her circle, she writes her own checks and pays her own bills. She develops her own shopping list, shops for her groceries and cooks her meals. She has grown closer to her family. She chooses her own clothes and cares for her pets. She understands money. During my visit, Becky checked on the goldfish and, finding that the fish food box was empty, she came back to the kitchen table and signed, "I need fish food and I have money." The words made my heart glad. "...and I have money." It certainly is not something you often hear from folks served within the system.

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The Journey Toward Self-Determination

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We sat at the table for quite awhile. As I sipped the last of my tea, I tried to engage Becky's cat, now sitting on the kitchen floor. I called to her but she did not respond. Then Becky began to sign and the cat jumped into her arms. My God, I thought, the cat knows sign! I looked over the table to Anna with a puzzled look on my face. "It's true," said Anna. "The cat only responds to sign." She explained that, when the first apartment was found, the roommate and staff played with the cat and talked to the cat. Soon the cat would not respond to Becky because she made no sound. She continued, "When Becky moved in here, the circle agreed to honor the fact that this is Becky's home and her language would be used. Sign is used here - and the TTY by everybody. It's only right." I apologized to Becky for not knowing her language. She signed, "It's okay." When I left Becky's house, I left smiling—smiling at the thought of a home where strobe lights are sentinels, language is a dance, and cats learn sign.

LINDA'S STORY

Linda invited me to her home on a sunny summer afternoon to talk about how her life has changed over the 10 years since we first met. When her housemate opened the door, I heard Linda's voice calling out to me, "Come in here. We'll talk in here." When I got to her room, I was struck, as I always was, with her beauty and her authority. "Get a chair," she said. Within seconds after sitting, Gloria, the cat, checked me out to make sure I could stay. "Do you have a cat?" asked Linda. "No," I said, "my husband got her in the divorce." We laughed. We started reminiscing about the TASH conference in New Orleans, where Linda gave a talk about how she has taken control of her life. "I had a ball!" she said. "Especially the casino and the food." She continued, "I won at the casino, but like a fool I put it in a machine and lost it all."

Linda enjoys a relaxing moment at home

When we began to talk about the past, Linda recalled lovingly the years she had lived with her family. She remains especially close to her sister, Jeanna. Then the smile left her face as she glanced over the bed to a photo on her bureau. Sadness blanketed her. She was silent for a moment, then she turned to me, smiled and said, "What else do you want to know?" Linda had also spent years of her life in two different institutions. "Laconia—now that was pure hell. I pray they will get rid of it so no one goes there again." After living in an institution, Linda was put into programs in the community, supervised 24 hours a day. "The first time I met you, you were living with Olga and a family out in the country." Linda took control of the interview. "Don't go there," she said, the smile having left her face. "Forget that." We moved on to how she began to speak out and change her life.

I asked how she made the dramatic transition in her life. "One day I said 'That's it!' and I started to speak up. People were at me all the time, running my life, day and night. I never was left alone. They controlled my life because I wouldn't speak up. They ran everything. I didn't have any say. I didn't have any money. So I told them I wanted to live by myself. I thought I wanted to live alone. I just wanted to have my life." We talked about Linda's job and the help she gets from aides 10 hours a week. "I have a home health aide and a homemaker. I decide who comes and when they come. I have a job. I work Tuesdays, Wednesdays, and Thursdays. My rate just went up, so I'll get more money soon! I have my own money. I pay my own bills and I do what I want."

She looked toward the kitchen. "The best part of my life now is him," she said, pointing in the direction of her housemate who was cooking hamburgers for lunch. "He is a big help to me in every way." Linda had spent years on a prone cart during the day because of skin breakdowns. "That cart... I hated it. I couldn't go anywhere or do nothin'. When I found out I didn't have to be down anymore, it was great." Linda has a motorized wheelchair now, with a special cushion that keeps her skin sound. "I see you tooling around town in that chair, Linda. You are all over the place!" She laughed. "Yes I am," she answered.

Somehow we began talking about the conference in New Orleans once again. "My strongest memory of your presentation, Linda, is when you were talking about how you spent your days. You said, 'With my man' and everybody in the room applauded." Linda looked at the photo on her bureau. "Now life is good. I wouldn't make any changes—except one," she said sadly. " I lived alone on Washington Street. They were years of hell. I don't want to live alone again. It's for the birds—living alone—and losing someone you love doesn't help either." She pointed to the picture. "His name was Duncan. He died last March. I'd describe him as lovable, sexy, sweet, kind, good looking, soft and cuddly. He was my friend. Losing Duncan broke my heart. He was special."

We talked for another hour, about love and loss, and soon it was time for me to leave. I asked her what message or advice she would give to other people who want to control their own lives. "I think people should be allowed to run their own damn life. When staff tell you what to do, you think you have to do what they say, but you don't. Just speak up. Tell them how you are going to live and that's it." The memory of that afternoon has remained with me every moment of every day since. Her insights, her wisdom, and her power will sustain her throughout her life, no matter what roadblocks may lie ahead, and what she gave to me will remain with me always.

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What's Happening Across The Country: Self-Determination in Action

There are self-determination projects funded by the Robert Wood Johnson Foundation in 19 states around the country. In addition, 10 states have recently received funds from the Foundation to implement technical assistance projects on the principles and implementation challenges of self-determination. Listed below are brief summaries of each of the original 19 state projects. Contact information is provided for each project. Following the project summaries is a list of the states that have received technical assistance funds, including contact information for those projects.

ARIZONA: "This is My Life: Arizona's Response to Consumer Control, Choice and Responsibility" is a project designed to infuse consumer control into the daily operation of the Division of Developmental Disabilities, Arizona's largest social service agency. The project represents a groundbreaking partnership with the state's Center for Independent Living to use a peer support model to jump-start systems change. Over the course of the project, fifty trained peer mentors will be matched with seventy-two individuals with developmental disabilities and their families. For information, contact Brian Lensch, Division of Developmental Disabilities, 602-542-0419; e-mail: bmlensch@worldnet.att.net

CONNECTICUT: The Connecticut Department of Mental Retardation will use grant funds to assist 125 people from all five regions of the state to engage in determining their own futures. The DMR will undertake organizational, program development, and training and technical assistance activities needed to support major systems change. For information, contact Terry Cote, Department of Mental Retardation, 860-418-6017.

FLORIDA: The Florida project will provide statewide education on self-determination and create a systems-wide culture of investment in systems change. Activities include the formation of an advisory/oversight team, creation of training materials, and the involvement of Support Coordinators, self-advocates and family members. For information, contact Pamela Aveling, 904-488-4877, ext. 125.

HAWAII: The State of Hawaii is developing a system that focuses on person-centered planning, participant management, support brokering, pooling existing resources, restructuring and quality assurance. Impact will be measured through the use of The Accreditation Council on Services for People with Disabilities' Outcome-Based Performance Measures. For information, contact William G. Christoffel, 808-586-4433 or e-mail: bchris@lava.net

IOWA: Iowa is developing a new required county planning process which assures the involvement of consumers and families, the formation of local project teams, assistance in modifying or developing the infrastructure needed to implement consumers' plans, a quality assurance system, and a set of standards for accreditation and licensing. For information, contact Janet Shoeman 515-281-4925, or e-mail: jshoema@dhs.state.ia.us

KANSAS: The purpose of Kansas' project is to examine the elements related to creating an infrastructure which provides an option for self-determination. The cornerstone of the project is the development of a method to make direct expenditures to, or authorize payment by, persons with disabilities. Project activities include creating a flexible funding stream, refining person-centered planning, and creating a culture which supports people who are turning hopes into reality. For information, contact Sharon Lobb Johnson, 913-296-3561, or e-mail: johnson@srmhdd.wpo.state.ks.us

MARYLAND: Maryland proposes fundamental change, moving toward a system in which people with developmental disabilities have control over supports and services they receive. Goals also include reducing the average cost of services and passing savings on to Marylanders currently on waiting lists. For information, contact Suzi Burke Harrison, 301-663-0909.

MASSACHUSETTS: The primary focus of Massachusetts' project is on individual outcomes including assuring that consumers know about opportunities for community supports and that decisions are made by the individuals being supported. Additional objectives focus on systems change internal to the State agency and systems change as it affects provider agencies, individuals and families, and the cost of services. For information, contact Hans H. Toegel 617-624-7781, e-mail: hans.h.toegel@dmr.state.ma.us

MICHIGAN: Michigan's initiative is intended to promote the evolution of a system of long-term support which is

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Self-Determination in Action

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cost-effective, socially and culturally responsive, and beneficial to all. Envisioned are systems of support that are consumer-driven and which promote satisfied customers becoming contributing members of communities, as opposed to perpetuating long-term dependence on segregated treatment models. For information, contact Michael J. Head 517-335-0276, e-mail: head@state.mi.us

MINNESOTA: A primary goal of the Minnesota Self-Determination Project is to demonstrate the implementation of comprehensive programs of self-determination at three sites. These programs will include person-centered planning, individually-controlled budgets, consumer-controlled housing, outcome-based quality assurance, and consumer education and support. For information, contact Barb Roberts 612-296-1146, e-mail: barb.roberts@state.mn.us

NEW HAMPSHIRE: The New Hampshire project will implement unique, regionally-specific strategies to develop organizational structures and financing strategies that will assist over 300 people to arrange and access responsive, personalized and cost-effective supports. For information, contact Mary-Ellen Fortini 603-271-5551.

OHIO: Ohio's Self-Determination Project focuses on four counties that were solicited through a competitive process. With assistance from the Ohio Department of Mental Retardation and Developmental Disabilities, each of the four counties will promote a series of activities in support of 223 individuals who will choose to participate in the self-determination process. For information, contact Cynthie Johnson 614-466-1907.

OREGON: The mission of the Oregon Self-Determination Project is to create a practical and affordable system of supports that is consumer-driven; makes use of innovative, flexible funding structures; and connects individuals and families to generic and natural supports. Under the project, approximately sixty individuals will choose and direct their own supports. For information, contact Laurie E. Powers, Ph.D. 503-232-9154, e-mail: powers@ohsu.edu

PENNSYLVANIA: Self-Determination efforts in Pennsylvania will be implemented in three counties. Each county will implement funding and program structures to ensure that decisions regarding services and system design are based on sound cost and utilization data, and that decisions regarding services are developed in partnership with customers, their families, advocates, and the provider community. For information, contact Edward R. Manning 717-787-3700, e-mail: erm01@epix.net

TEXAS: The Texas Self-Determination Partnership is a collaborative effort that proposes the implementation of self-determined individual budgets and support plans, an administrative structure that reflects the priorities of person-directed and outcome-oriented supports, and the development of a model for training and technical assistance. For information, contact Reena Wagle 512-206-5118.

UTAH: The Utah Self-Determination Project will transform the design and delivery by the Division of Services for People with Disabilities. By the end of the three year project, at least one-third of the Division's consumers will be exercising self-determination and 35 out of 44 providers will be providing self-determination focused supports. For information, contact Travis Wall 801-538-4190, e-mail: sgeary@email.state.ut.us

VERMONT: The Vermont project is statewide in scope and targets the achievement of real consumer choice and control. The project provides direct support and training to people with disabilities and their families, advocates, and service providers on implementing individually controlled budgets, making informed choices, and resolving technical, payment, liability, funding and support issues. For information, contact Michelle Sures 802-241-2614.

WASHINGTON: Over the course of three year project, the Washington project, known as "Composing a Life" will identify sixty families or individuals to participate in a personal planning process. An action plan will be developed and implemented that centers on the person and that may involve service providers, generic supports, or natural supports. For information, contact Lyle Romer, Ph.D. 206-685-7121, e-mail: lromer@u.washington.edu

WISCONSIN: Three primary sites have been identified in Wisconsin. These are, Winnebago County, LaCrosse County, and Dane County. Each county has developed specific plans for effecting self-determination in Wisconsin. An additional 15-20 secondary sites will be selected to serve as learning sites. For information, contact Jan Devore 608-267-7858, e-mail: devorjk@dhfs.state.wi.us

States Receiving Funding for Technical Assistance Projects

Alabama - For information, contact Robert Cotton, 205-554-4155
Colorado - For information, contact Judy Brown, 303-866-7450
Georgia - For information, contact Collier Cato, 912-743-9801
Idaho - For information, contact Russell C. Spearman, 208-334-2178
Louisiana - For information, contact Bruce C. Blaney, 504-342-0095
New Jersey - For information, contact William C. Gaventa, 732-235-4408
New Mexico - For information, contact Randy Costales, 505-883-4630
New York - For information, contact Margaret Sellers, 518-473-9697
North Carolina - For information, contact Megan Soyster, 919-733-6566
Tennessee - For information, contact Ruthie-Marie Beckwith, Ph.D., 615-256-8002

To request complete summaries of each state's project and further information on state contacts, call TASH: 410-828-8274, ext. 101; or e-mail: selfdetermination@tash.org. Please indicate your specific request.

Video Taping Self-Detemination Is Ohio's Visual Yardstick

BY KIM SHERIDAN

The Ohio Department of MRDD is one of the nine fully funded states participating in the three-year Robert Wood Johnson Foundation's Self-Determination Project. Under Director Jerome C. Manuel, Ohio is undertaking an unusual approach to documenting this project.

"Would you like to see my inspiration?" Patricia poses the question with a gleam in her eye to the four people clumped around her computer. She has been taking us on a tour of her home, pausing time and again to make sure we understand how thrilled she is to be in this home, her home, after 17 years in an institution. The hallways in her wheelchair-accessible home are lined with framed works of poetry Patricia has authored over the years. She is an accomplished poet, published and the recipient of several awards. Patricia has taken us into her office to show us her computer. She'd show us how she uses her mouthpiece to operate it, but the computer has been down for two weeks, awaiting a visit from the repairman ("I have to wait for him to get around to me," she says in her matter-of-fact manner). We indicate that yes, we'd like to see what inspires this attractive, forty-three year old woman who waits patiently for others to do what she is unable to do for herself. With that, she invites us to close the door to the office. On the back of the door, several posters of toned, tanned young men smile back at us from their pose on the beach or in the gym. As inspirations go, Patricia has chosen a classic.

Patricia lives in Toledo in Lucas County and is one of many participants in the Robert Wood Johnson Foundation (RWJF) Self-Determination Project. Proposals for this project were submitted to the Foundation from 38 states. Under the direction of Director Jerome C. Manuel, the Ohio Department of MRDD (ODMRDD) was selected as one of nine fully funded states for the three year project beginning in 1997. The states received partial funding and since the initial announcement of recipients, an additional eight states have received small funds from RWJF to explore self-determination. ODMRDD requested proposals from the 88 county boards of MRDD in Ohio, and four counties, Delaware, Knox, Lucas, and Marion, were selected to receive RWJF funds. The four counties represent a mix of urban and rural settings, and typify the challenges facing county MRDD boards in Ohio as they move away from the role of service provider to more of a broker of supports to individuals and their families. Though only four counties will actually be receiving funds for this project, virtually all 88 countries are seeking ways to practice the principles of self-determination.

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One of the best ways to show change in someone's life is to do so visually...

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When the grant award was announced, ODMRDD began to look at ways to document self-determination that would reflect Ohio's unique system of county-administered services and supports. One of the best ways to show change in someone's life is to do so visually, and ODMRDD decided to produce a visual document, recording a person's life at the beginning, middle and end of their participation in the self-determination project. Director Manuel committed funding to produce such a visual document in Ohio, and the National Program on Self-Determination for Persons with Developmental Disabilities put funds into this video taping effort as well.

"Ground Zero" footage is presently underway in each of the four counties. Counties had already selected participants for self-determination by a variety of methods including a lottery, consumer advisory groups, and referrals. From these project participants, ODMRDD selected three individuals from each of the four counties to participate in the video taping process. Those selected represent a cross section of individuals and family members presently served by a county MRDD board. The taping is being done professionally, and it is anticipated that footage shot over the next three years will be made into a television documentary on self-determination. At present, or "ground zero," each participant's life is being captured as completely as possible through extensive on-camera interviews with the individual, and significant people in his or her life, such as family members, support staff, friends, etc. ODMRDD proposes to return in one year to video tape any progress, or set backs, that have transpired, and then tape again at the end of the three year self-determination project for wrap up footage.

The video taping project will capture many unusual events, such as planning meetings, where the individual and invited others set up a life plan, discussing dreams, and mapping out measurable goals. Interviews have revealed the gamut of good and bad things in a person's life, and the emergent stories are poignant and telling.

Patricia lived for 17 years in an institution for people with disabilities. She went to the institution when her mother felt she could no longer handle caring for Patricia at home, her father and siblings having long ago walked away from the family. When asked what it was like, Patricia responds, "It was hell. I could do nothing for myself. I couldn't even cross the street." Forced to live

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Video Taping Self-Detemination Is Ohio's Visual Yardstick

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under the rules and restrictions imposed by others, Patricia rebelled. "I've got a very sharp mind. I needed my freedom. I broke a rule everyday," she says. For 12 years, she fought to get away from the institution, working for years through red tape, Medicaid rules and case managers. Now, Patricia lives in a house with a roommate. "Most people thought I could never do this. 'You won't make it, you need too much help, you can't even feed yourself.' And now look at me. I have my own home."

Patricia responds, "Like it is now, with a job. I need a job for my self-esteem." Patricia would like to design and compose greeting cards. Her case at the Bureau of Vocational Rehabilitation has remained open for three years. So far, no opportunities have come knocking.

In Knox County, we meet Shelia, a pleasant woman in her mid-thirties. Shelia has worked for many years in the workshop run by the Knox County Board of MRDD, but is about to undertake a new adventure in her vocational career. Shelia and another woman will be starting their own cleaning business. Staff at the county board recognized Shelia's ability and desire to work in a community setting, and paired her with another woman who will act as a helper to Sheila on the job. Shelia is nonverbal, and requires some prompting to stay focused on the job. With the assistance of county board staff, the women received a grant to purchase the equipment for their business, as well as money for a van to haul it around the county. Those who know Shelia well think this a great opportunity for her to grow and meet others outside the small circle of her present life. Shelia lives in a group home with four other women. We visit the home and ask about Shelia's life. Each lady has her own room, but activities and meals are undertaken together. "Puzzles are Shelia's life," the house manager tells us. When asked if Shelia has ever confided dreams and desires, we are told, "She's not that kind of a person. She doesn't think about the future. She is a happy person and lives day to day." The owner of the group home is asked if one of the ladies wanted to live somewhere else, could they do so? "I'm like an old mother hen," he replies. "I would be upset if they wanted to leave, but I would try to work it out."

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each participant's life is being captured as completely as possible through extensive on-camera interviews with the individual, and significant people in his or her life, i.e. family members, support staff, friends, etc.

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While in Knox County, we also meet Ryan, and talk with him about his life. Ryan is 25 and lives at home. He loves sports, and desperately wants a job involving sports. At the time we meet him, he is volunteering his time at a kid's summer basketball camp at a local college. His rapport with the kids is evident, and they shoot baskets around his electric wheelchair as he buzzes across the court. Ryan presently works at the workshop also, but he does not like it. "It's too noisy," he says. He wants a job in the community. He also wants a girlfriend. We ask him if he has friends and does he get out to meet people, and he says no. His parents take him places. We then learn Ryan is a twin. He hasn't seen his brother in seven or eight years as he lives in Indiana. They talk by phone once in awhile. Ryan doesn't even know if his brother is married. When asked if he misses him, Ryan responds sadly, "I miss him very much."

We met Tony, the first participant in ODMRDD's self-determination video taping project in Marion County. Tony has recently celebrated his 45th birthday, and tells us during his interview that there are many things about his present life that he wants to change. Tony has difficulty in speaking and being understood, so he has asked Chris, a staff person he is close to at the Marion County Board of MRDD to help interpret. Tony is very clear about working at the workshop. "I don't like it," he says. "It's noisy, and I don't make enough money." Tony lives in a group home with four other people. Do you like it, he is asked? "Uh uh, no way! People yell and push me." Tony has a mother with health problems, and several brothers and sisters. They are all very happy with Tony's living situation. Chris says it's a dilemma for staff who want to help Tony live in a place of his choice. Chris is working to help bridge the gap between Tony's desire to live independently and his family's concern that Tony is better off where he is now. We ask Tony about his dreams for his life. "I want a house, a wife and a family." Tony does not have a girlfriend, nor does he have the opportunity to meet women other than those he sees at the workshop. When asked if he has the ideal wife in mind, Tony says, "A sexy blonde." He also indicates she'll be the one to mow the lawn and cook. Tony, however, will do the dishes.

About a month after we talked with Tony, Chris had an update. Tony's family is willing to think about a more independent life-style for him if Tony can find gainful employment. Tony has expressed a desire for his own business, and Chris and Tony have devised a plan to purchase a cart from which Tony will sell coffee and pastries. Tony's group home has also taken an interest in his efforts to be self-determined and is building a separate wing on his current home so he can have his own living space.

In Delaware County, we meet our first child participant in the project. Brianna is five years old and part of a large, boisterous family of five siblings. Our meeting at the family home is marked by chaos, with everyone anxious to be heard and attract attention, including Harley, Brianna's canine. Brianna's service coordinator from the Delaware County Board of MRDD, and her teacher at school round out the small army of people gathered on a summer's afternoon

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to talk about Brianna's life. Brianna's parents are involved in every detail of her life, and are determined that Brianna have the same shot at life as their other five kids. Brianna has cerebral palsy, and is in need of several expensive items that will increase her independence, such as an electric wheelchair and a communication device so she can talk to her family. Her parents are applying for a Medicaid waiver that will provide assistance in purchasing these items. After learning the cost (not to mention the waiting period) to get a canine companion through an agency, Brianna's mom got Harley, a German Shepherd, as a puppy, and hired a trainer to work with Brianna and Harley to help them become partners in greater independence. Harley will accompany Brianna to school this Fall, a first for the school. The entire family is involved with Brianna, and mom and dad admit it is stressful on everyone. "It's so difficult for families," says Brianna's dad. "Just to get even basic information about your child's disability and where to get help is hard enough." Brianna's mom adds, "There's so much paper work. All the assessments every year. Her situation is not going to change. She has CP and will for the rest of her life. Why do we have to go through this every year?" Funding remains the greatest challenge. "Just because we own a home doesn't mean we can afford an electric wheelchair," says Brianna's mom. "We're exploring every avenue of funding we can." She looks over at her youngest daughter who is shrieking with laughter as one of her brothers torments her. "She has a good little mind, and is capable of telling us what she wants. She just needs the device to be able to do that."

Kim Sheridan is Chief of the Office of Public Information of ODMRDD. With a background in film production, Ms. Sheridan is producing, directing, and writing this video documentary project. If you would like more information on this project, she can be reached at (614) 644-0262.

Disability Leaders and Self-Advocates Meet To Plan The Future Of Self-Determination For Persons With Developmental Disabilities

For three days in September, close to 300 participants from across the country met in Tempe, Arizona to share strategies for self-determination systems change. Participants from 38 states included self-advocates, family members, state agency heads, staff and providers working together to shift the control of service dollars to individuals, build inclusive communities, and target dollars to better support people with developmental disabilities.

Under self-determination, not only do persons with developmental disabilities plan their own supports, they learn to choose, with the help of family and friends, an array of supports that most fit personal needs. At the gathering in Tempe, national leaders within the self-advocacy movement, like Chester Finn, President, Self-Advocacy Association of NYS, Inc., spoke to the gathering on what self-advocates want for their lives in the community. Finn stressed that like everyone else, individuals want to choose where they live; what jobs they have; where and how they socialize; and what friends they have. The times of being told which predetermined services are being provided for individuals with developmental disabilities should be in the past; the days of institutionalization should be gone.

Again and again during the conference the word "choice" was celebrated - in videos being produced by the Ohio Self-Determination Project for the National Program Office; in workshops led by self-advocates such as Bernard Baker, Pat Hornick and Jimmy Wilson; in plenaries given by leaders like Bob Gettings, Director of the National Association of State Directors of Developmental Disabilities Services, Inc., and Bob Williams, Deputy Assistant Secretary of HHS, Office of Disability, Aging and Long-Term Care Policy.

Speakers and participants focused on "Peer Support in Building a Self-Determination Learning Community," facilitated by Tom Nerney, Co-Director of the National Program Office on Self-Determination, and Dennis Harkins of Wisconsin - who looked at "responsibility" in self-determination.

"Self-determination is proving to be a practical cost saving alternative to previous programs that in essence warehoused people with disabilities" said Don Shumway, Co-Director of the National Program Office on Self-Determination. "No one does a better or less costly job of determining their own future than those who are most affected." The national program is co-directed by Shumway and Nerney out of the Institute on Disability/UAP at the University of New Hampshire, and funded by The Robert Wood Johnson Foundation of Princeton, New Jersey.

The conference brought together leadership from the National Program Office and the 19 states (including host state Arizona). The states were awarded over $5 million to design and implement their new systems. An additional ten organizations have received technical assistance funding from the national project and many participated in the conference. At the annual conference participants learned that states are approaching systems change in different ways, and each shared its respective plans for implementation and results. Participation of self-advocates was a most important and integral part of the conference on self-determination. Family members, Washington, DC-based policy makers and national advocates views were aired. Participants heard as well from former Assistant Secretary of OSERS, Madeleine Will, currently Vice President of Community Options, and from Joe Shapiro, Senior Writer at US News and World Report (author of NO PITY, a chronicle of the disability rights movement) on the politics of self-determination. A needed vantage point on managed care - "What Managed Care Companies Know that we Don't - but Should" - was addressed by Marc Fenton of Public Consulting Group, Inc.

A key component for success in self-determination must include job choice, skills and training. Participants heard from experts at the new disability initiative at the US Department of Labor and from Massachusetts on national and local efforts to include people with disabilities in the work place and the initiatives and strategies that will most impact the self-determination movement. Other areas covered in workshops included: Revising Medicaid Waivers to Enhance Self-Determination; Brokering; Fiscal Intermediaries; Individual Budgets: Doing More for Less; Investments in Our Future; Place, Neighborhood and Community; Strategies for Systems Change; Building a Movement for Self-Determination; and many more.

The Arizona conference was the first annual gathering of states developing self-determination systems change projects. The Robert Wood Johnson Foundation, one of the largest US philanthropies devoted to health care, has created its first national program devoted to people with developmental disabilities. Challenges lie in the implementation efforts at the state, local and individual levels. The conference provided a forum for sharing and learning for the coming years.

The Michigan Approach

The Best Of Managed Care and Self-Determination

BY JAMES K. HAVEMAN, JR. & MICHAEL J. HEAD

Can managed care and self-determination co-exist? In Michigan, we think so. In fact, we are counting on it. Michigan is poised to move funding for public mental health services, including services/supports for persons with developmental disabilities, into a managed care arrangement. In January, 1998, the Michigan Department of Community Health will enter into contracts with each of the 50 local Community Mental Health Services Programs (CMHSPs). These contracts will serve as vehicles for providing pre-paid, capitated funding, using a combination of Medicaid and state funds. Responsibility for managing funds for services/supports will be located at the CMHSP level. Michigan is currently negotiating the necessary Medicaid waivers with the Federal government.

Michigan's Self-Determination Initiative is an important piece of planning for managed care. Michigan is one of the 18 states participating in the Self-Determination for Persons with Developmental Disabilities project, funded through the Robert Wood Johnson Foundation. Michigan's Self-Determination Initiative project sites are making fundamental system changes by implementing consumer-managed service/supports. These arrangements are being constructed within the managed care financing framework which each local system must have in place. The opportunity to create cutting edge approaches which give people meaningful choices, and control over their lives, has generated excitement at each of the Self-Determination sites. A strong commitment to base the resources allotted for supports on what a person wants for his/her life and then give them control over directing those resources, drives each local coalition in Michigan's Initiative. Self-determination, based upon the person assuming a certain amount of risk, in exchange for the opportunity to determine how best to obtain supports, is where managed care must evolve. The principles of self-determination - - freedom, authority, support and responsibility - - are central to using managed care in ways which lead to better use of public resources.

In 1996, Michigan made the decision to apply managed care to all its health and mental health care services. Primary health care costs could not continue their unchecked upward spiral. Without substantial change, a future of flat funding could not meet the needs of people with persistent mental illness or a developmental disability. "Business as usual" was going to require either reductions in services or restriction of access through limitations on eligibility. Michigan chose to work smarter through an across-the-board plan for implementing managed care. Planning for managed care has been an open and inclusive process. To be sure, there are concerns about how the transition process will unfold. Very few, however, oppose these new directions.

Elements of managed care have been present in Michigan's system for over 15 years. Local CMHSPs shouldered the risk associated with managing a predetermined level of funding as they developed community services to replace reliance on institutional care. Michigan trusted the community system to lead deinstitutionalization efforts. They, in partnership with advocates and community leaders, created the current services/supports network, allowing Michigan to achieve one of the lowest levels of use of large, segregated facilities - public or private - in the nation. The result has been a broad array of residential homes, workshops and day programs managed by community providers. In certain areas, major strides have been made in supporting people to live independently in their own homes, obtaining integrated work through supported employment, and increasing community participation. But we have far to go.

Managed care is seen in some circles as restrictive and controlling; limiting meaningful options for people. Critics feel that managed care is all about saving money, where budgets are balanced on the backs of vulnerable people. In Michigan, managed care is seen as a catalyst for new opportunity. This opportunity comes in part from introducing more competition to service systems which are currently

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Michigan: The Best Of Managed Care and Self-Determination

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agency and provider-dominated. Local mental health services management has been the exclusive purview of county-based CMHSPs. Michigan's managed care requirements for the mental health system include performance and outcome requirements as well as a readiness review process, and the application of consumer feedback. Such features demand responsiveness from the local CMHSP. Michigan has, overall, had great success in meeting the needs of citizens through its publicly managed mental health system. As managed care is implemented, however, maintenance of the local franchise is not guaranteed if performance is unacceptable.

Several major components of Michigan's managed care framework for its mental health services are aimed at supporting people, not maintaining bureaucracies. Among these are the emphasis on outcome, and re-orienting power toward the consumer. This policy direction involves introducing criteria which promote consumer participation in what has been a rather monolithic local structure. Standards for local quality management systems include use of consumer feedback and panels of consumers and family members which review this feedback and formally comment on service system functioning. Amendments to Michigan's Mental Health Code now require that local CMHSP Boards be composed of at least one-third consumers and family members.

These Code amendments also support people in the context of managed care. In Michigan, each eligible person who comes to the public mental health system for services/supports must receive an individualized plan developed using a person-centered planning process. This requirement, introduced with the support of Michigan Governor John Engler, and adopted by the Legislature, was formed in partnership with consumers and advocates. Their experiences with the 'system' showed that too much of a person's life was prescribed by professionals and providers; too little was based upon what the person wanted his/her life to be. People who need support from the public mental health system are, in a sense, held captive in highly structured and regulated arrangements under which they learn little about choices and how to make them. Another Code amendment allows the issuance of vouchers to consumers, based upon their plan of services/supports. This option, together with the person-centered planning process, is an important piece of the framework Michigan is using to construct a system which advances self-determination.

Self-determination is thus at center stage in Michigan for people with disabilities. Criteria requiring person-centered planning, permitting the use of vouchers, and introducing consumer-managed service/support arrangements all aid in transferring control over lives from organizations, to people. Michigan's Self-Determination Initiative aims to give people what they require to have the life they choose, staying within current resources, and giving the person and those closest to him/her the authority to control how resources are applied.

In Michigan, self-determination will help modify practices which shelter people with disabilities in prescriptive and costly provider-controlled group home systems. These systems, while located in communities, are separated from community and tend to promote and maintain dependency. Too often, little consideration is given to what a person really wants or needs to have a life with meaning. Giving people the freedom to learn about and make choices concerning their supports is rooted in using a person-centered planning process. This process is the basis for reaching agreements about how public funds will come into play. The opportunity for the person to exercise authority over a pre-determined level of resources, including the opportunity to experience failures and to learn from these, promotes a greater measure of personal responsibility for one's life.

Will there be cost savings? We believe the answer is, "yes". These savings will emerge from the individual choices made by people now in highly structured, intensively regulated and expensively programmed group living arrangements. Our experiences demonstrate that, when people choose supports to live the life they want, they often choose less than the "system" currently prescribes. Savings could be used to address unmet needs for those waiting for services/supports.

Is this all too optimistic? We don't think so. We do know that large service systems do not change very rapidly of their own volition. As managed care is implemented, we will learn how to make self-determination work in concert with it and to apply what we are learning to give consumers and their families real authority over their lives. People learn to be responsible when they have the authority to exercise freedom over their choices, with support to pursue their own lives.

Mr. Haveman is the Director of the Michigan Department of Community Health, which has combined responsibility for mental health, public health, substance abuse, aging and long-term care services, and Michigan's Medicaid program. Mr. Head is manager of Michigan's Self-Determination Initiative.

The Journey Toward Self-Determination

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The idea is a simple one. It is as basic as human nature itself…the desire to live the life we have been given. It is, in fact, the most fundamental human right. It is freedom. Yet most who are served within human service systems remain far removed from the ways in which others in this society live. They live lives contrived and programmed, lives which have been built to satisfy the system rather than the soul…lives which those who make the rules would not be willing to live for a single day. When the soul struggles to break free, behavior plans are imposed, medications are prescribed, and labels are attached—labels so intrusive and limiting that it is a testament to the human spirit that people thus burdened continue to exert their own power.

That which should be simple and basic becomes complicated by elaborate bureaucracies, regulatory mazes, fiscal complexities, governmental intrusions, professional idiosyncrasies, and societal prejudices. Yet with all of these pressures, throughout the country, those who work supporting people who have disabilities are examining their bureaucracies and rules, their attitudes and regulations. People who have disabilities are discovering their power and their abilities, their hopes and their dreams. Their abiding inner strength is providing a ground swell of life as the nineteen self-determination projects present opportunities for real change in the systems which provide support.

Ellen Cummings is a national consultant, providing technical assistance and training to those who are implementing self-determination principles in their systems and in their lives. She can be reached at 603-363-4656; fax 603-363-8141; e-mail: ellenm@sover.net; or by writing to P.O. Box 569, Spofford NH 03462.

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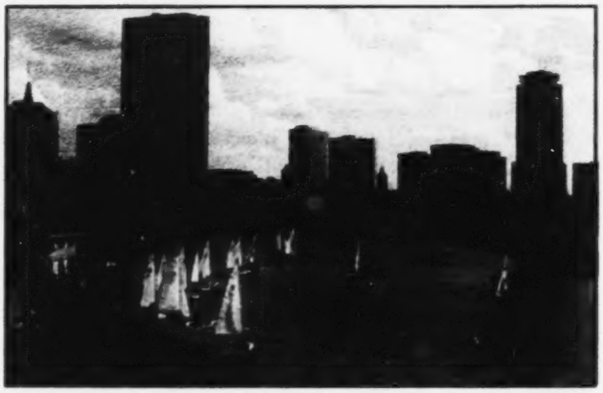

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To obtain the discounts, you or your travel agent must call US Airways Meeting and Convention Reservation Office at 800-334-8644; 8:00 am – 9:00 pm Eastern Time. Refer to Gold File No. 77680250.

Last year over 50 people with disabilities and/or family members of people with disabilities were able to attend the conference because you stayed at the TASH headquarters hotel and/or used the official airline. Thank you! Let's continue that effort and make it possible for even more people to attend this year's conference in Boston. Make your reservations early — the holiday season is a busy time for an exciting place like Boston — don't delay, do it today!

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- *Increasing the Impact of Grassroots Advocacy*
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- *Eliminating All Obstacles to Full Inclusion*

Tentative Conference Agenda

TUESDAY, DECEMBER 9, 1997

8:00-9:30 PM Pre-Conference Registration Open

WEDNESDAY, DECEMBER 10, 1997

7:30-9:00 Pre-Conference Registration

8:00-4:00 Club TASH Day Care/Youth Activities

9:00-4:00 TASH Tech Pre-Conference Workshops

9:00-4:00 TASH Chapter Development and Leadership Day

2:00-8:00 PM General TASH Conference Registration

5:00-7:00 PM Opening Reception in the Exhibit Hall , light fare will be served w/cash bar

THURSDAY, DECEMBER 11, 1997

7:30-3:00 Tash Conference Registration

8:00-5:30 Club TASH Day Care/Youth Activities

8:00-5:00 TASH Exhibit Hall Open

8:00-3:15 Conference Sessions and Poster Presentations

3:30-5:45 Plenary Session

5:30-7:00 Open Reception-Hosted by New England Chapter of TASH (light fare will be provided, drinks available at the cash bar)

FRIDAY, DECEMBER 12, 1997

7:30-11:00 Tash Conference Registration

8:00-5:30 Club TASH Day Care/Youth Activities

8:00-5:00 TASH Exhibit Hall Open

8:00-3:15 Conference Sessions and Poster Presentations

3:30-5:45 Plenary Session

6:00-7:30 Open Reception in Honor of Lena Saleh, Chief of Special Education, UNESCO-PARIS, Sponsored by the Gunnar & Rosemary Dybwad Foundation and The Federation for Children with Special Needs (light fare will be provided, drinks available at the cash bar)

8:30-10:00 Songs of Liberation and Community

SATURDAY, DECEMBER 13, 1997

7:30-9:30 Tash Conference Registration

8:00-2:00 Club TASH Day Care/Youth Activities

8:00-2:00 TASH Exhibit Hall Open

8:00-2:00 Conference Sessions and Poster Presentations

8:00-3:00 Full Day Special Mini-Conference "Teaching Students with Significant/Multiple Disabilities in Inclusive General Education Settings"

For a copy of the full schedule of sessions for the conference, please call 1-800-482-8274.

THE TASH CONFERENCE WILL FEATURE THESE SPECIAL SESSIONS ON SELF-DETERMINATION:

Walking the Talk: Making Self-Determination a Reality

Ellen Cummings - A realistic discussion of how to implement self-determination in the face of multiple obstacles. Using nine Principles for Action, it is possible to make the changes needed in ourselves and in the system, and to maintain integrity on the journey. Ellen has a wealth of experience in the area of self-determination and will share stories and insights which illustrate creative responses to problems, as well as issues involved in transferring power and authority.

Join members of The Lively Lifelines Integrated Training Group, a group of self-advocates from New Hampshire for a discussion of what self-determination has meant to them.

Self-Determination Roundtable #1 - Federal, State and Agency Policy Challenges to Implementing Self-Determination

Facilitators: Tom Nerney and other participants in self-determination projects from across the country. A participatory discussion of the public and agency policy issues that present obstacles to the transition to self-determination. Issues to be discussed include: Medicaid regulations, state policy changes that facilitate self-determination, the development of support broker systems, personnel issues, and fiscal mechanisms that support consumer-controlled budgets, etc.

Self-Determination Roundtable #2 - Getting Personal: Supporting People Who Are Tough to Support to Lead Self-Determined Lives

Facilitators: Suzi Harrison and Mike Smull. An participatory discussion of the difficult issues in supporting people who have challenging behaviors or who don't communicate in traditional ways to design and achieve lives of their own. Issues to be discussed include: individual planning, supporting people to make and maintain connections with friends, family and the community, when people's choices challenge the system and the people who provide support, etc.

Moving From Good Ideas to Good Lives

Representatives of The Southern Collaborative, a group of self advocates representing People First of Alabama, People First of Georgia and People First of Tennessee will present a training kit they have developed focusing on the obstacles to achieving self-determination and ways to overcome them. *Lee Ann Boyce and Beth Dunn.*

Managed Care and Self-Determination: Working Together in Michigan

Dohn Hoyle. Many people view self-determination as a great idea but fear it will be prohibitively expensive. In Michigan, self-determination and managed care are not viewed as mutually exclusive approaches to serving people with long-term support needs. Michigan's self-determination project is demonstrating that individuals will make cost- and benefit-effective decisions about the resources and supports they require when afforded the opportunity to make informed personal choices.

CHECK OUT THE GOVERNMENTAL AFFAIRS STRAND AT THE CONFERENCE:

The work of TASH is guided by our members. It is important to take the opportunity at the Conference each year to give and get current information about the local, state and national issues that concern us, and to plan our work for the coming year. This year, the Governmental Affairs Strand features information and updates on several issues, skillbuilding workshops and an opportunity to participate in action planning with others committed to the same issues. Topics to look for include:

- The Close the Doors Campaign
- Medicaid and Managed Care
- Private Insurance and Managed Care
- MiCASA (HR 2020)
- Immigration and Disability
- Update on Children's SSI
- Update on Employment
- Physician Assisted Suicide
- The Mission, Goals & Legislative Plan of Californians for Inclusive Schools
- Building Coalitions at the local, state and national level
- IDEA 97 Questions & Answers with the Director of the Office of Special Education Programs
- Strategies for Parents to Influence the Political Process
- What's in the IDEA Regulations Draft and How to Influence the Final Regulations
- Update on the Rehab Act
- Understanding your rights and responsibilities under ADA
- How to use IDEA 97 to improve monitoring, implementation and enforcement of the law.
- IDEA, Positive Behavioral Support and a Model Statute/ Regulation.
- Government's Responsibility for Monitoring after the Closure of an Institution
- Medi-Cal & Special Education Funding
- Focus on the California Moratorium on Community Placements
- The Changing Face of Grassroots Advocacy

5TH ANNUAL COMMUNITY LIVING GATHERING

Host: TASH Community Living Interest and Action Group,
Convened by: Lynda Baumgardner

The Gathering is a place for everyone to create a forum in which interests and concerns relating to community living can be heard. This is your change to get together with others to set an agenda in which the burning issues that are important to you can be discussed. Past year's agendas have included such topics as circles of support, multicultural issues, roommates, family issues, employment, support issues and much, much more. **There will be some pre-advertised sessions throughout the conference (check the conference program on-site), but the specific agenda will be developed on Thursday morning during the opening session.** The opening will be at 9:00 am and will be with Herb Lovett, Judith Snow, and Jay Klein. The Gathering runs throughout the entire conference-come and go or stay all day!

TASH TECH PRE-CONFERENCE FULL-DAY SEMINARS

TASH Techs are optional full day pre-conference seminars that offer opportunities for in-depth exploration of important topics. See the registration form on page 27-28 for information on fees and registration. Space is limited.

T1 Policy and Systemic Issues Regarding Performance and Supervision of Paraeducators and Direct Support Professionals

Patricia Mueller, Anna Lou Pickett, Amy Hewitt

Participants in this TECH will receive information that will enable them to more effectively build and sustain teacher-paraeducator teams. Topics to be addressed include distinctions in teacher-paraeduca-tor roles; paraeducator skills and competencies; the role of teachers as supervisors of paraeducators; and resources.

T2 Inclusive Classrooms as Total Learning Communities

Mara Sapon-Shevin, Mary Fisher, Lucille Zeph

"Best practices" in general education - multilevel teaching, multiple intelligences, portfolio assessment, integrated or thematic instruction, cooperative learning and community building, are consistent with, and supportive of, the efforts to include students with significant disabilities. Critical elements supportive of the inclusion process will be discussed.

T3 Seeing Competence: Challenging Our Deficit Approach to Understanding and Supporting Individuals with Autism/Mental Retardation and Other Communication, Movement, and Behavior Challenges

Anne Donnellan, Phillip David Zelazo, Margaret Bauman, Michael J. Solomon Weiss, Martha Leary, Karen Strandt-Conroy, Sally Young, Madeline Hafner, Jean Hauser, Victoria Moerchen

Current models of assessment and support emphasize deficits rather than assume competence. The assumption and misunderstandings behind these deficit approaches will be discussed, as well as newer ways to assess, support, and communicate with labeled individuals.

T4 Public Schools and the Americans with Disabilities Act (ADA)

Kathy Gips, Melissa Marshall

Confused about school districts' responsibilities under the ADA and the ADA's relationship with Section 504 and IDEA? You are not alone. The requirements and gray areas of the law will be clarified.

T5 Curriculum Modification and Communication Supports TOGETHER in the Inclusive Classroom

Cheryl Jorgensen, Rae Sonnenmeier

Participants will practice techniques for analyzing opportunities for learning and communication in several general-case regular classroom situations, and for planning curriculum modification and communication supports that promote full participation. Target audience: teachers and communication specialists who work at the preschool – high school level.

T6 Specific Strategies to Support Friendships and Community Connections for People With and Without Disabilities

Angela Novak Amado

Stories, slides and specific "How To" strategies will be presented about how to support relationships with non-disabled community members. Lessons successfully used in residential, vocational, urban and rural areas, including individuals who have been labeled as having significant disabilities will be presented.

T7 Including Students with Disabilities as Fully Participating Members of the High School Community

Carol Tashie, Mary Schuh, Susan Shapiro Bernard

Why students with disabilities should spend their high school career with all peers, and strategies for overcoming obstacles that cause students to spend time away from typical peers will be discussed. What students should be learning in classes; after-school; weekends; and the transition to jobs will be presented.

T8 Inclusive Classrooms: Accessing the Opportunities of Whole Class Instruction

Christine Salisbury, Ginger Joyce, Toni Strieker, Deborah Tweit-Hull

Emphasis is on how to adapt general education units such that whole class instruction occurs and teachers are kept from preparing and implementing separate lessons for students with unique learning needs. Information on how to keep the curriculum, instruction, and assessment flexible, meaningful and challenging to all students will be included.

T9 Preparing Teachers for Inclusive Schools: Strategies for Change within Higher Education

Gail McGregor, Dianne Ferguson, Alison Ford, Beverly Mattson

This session is designed to engage individuals working in higher education in discussion and action planning around preparing teachers to work in inclusive schools. Efforts to change current practices at multiple levels: within individual classes; within departments; cross-departments; cross-universities; and at the state level will be highlighted.

T10 Assistive Technology: From Policy to Reality

Katherine Inge, Karen Flippo

Assistive technology (AT) is a powerful force for inclusion of people with disabilities in schools, businesses, and communities. This session provides a comprehensive evaluation of AT policy; policy implementation; funding of technology; and observations regarding the challenges that individuals are facing finding jobs and making needed adaptations in the workplace.

T11 Homeownership: A National Initiative

Jay Klein , Marcie Goldstein, Judith Snow, Joe Wykowski

People with disabilities are often not afforded basic choices about where they live and are amongst the most underserved group in the mortgage industry. This session is designed to provide individuals, families, lenders and professionals with strategies used by local coalitions throughout the United States to help individuals to own their homes.

T12 From Paternalism to Reciprocity: Putting "A Credo of Support" into Daily Practice

Mayer Shevin, Nancy Kalina

In their videotape " A Credo for Support," Norman Kunc and Emma Van der Klift describe a basis of connections that are not hierarchical social roles of "expert," client, "guardian, "etc.; rather a relationship based on respect, common humanity, and shared membership in each others world. There are still many questions when trying to implement this commitment. This session will provide a setting to frame and struggle with the questions.

T13 Making Meetings Matter

Marsha Forest and Jack Pearpoint

Make Your Meetings Matter. Practical and usable tools for running efficient, effective, creative and meaningful meetings anywhere & everywhere for all organizations. Everyone faced with running a productive meeting is encouraged to attend.

T14 Changing a Human Service Agency

Jeff Strully, Tara Asai, Patricia Fratangelo

This pre-conference session will focus on three different agencies that successfully converted all of their services to individualized, personalized, and valued supports. The session will provide specific strategies, methods, insights, reflections and stories on how to change the way you "do business."

T15 The Process of Positive Behavioral Support with Families in Natural Contexts

Bobbie Vaughn, Kathy Ben, Glen Dunlap, Joseph Lucyshyn

This session is for families of children with disabilities who display problem behaviors, and for professionals who offer behavior support to families. Four concepts will be emphasized: family-professional partnership; lifestyle change/outcomes; comprehensive assessment, functional assessment, and family ecology assessment; and contextually appropriate, multi-component support plans.

T16 Family-Centered Approaches in Early Childhood

Susan Yuan

Families of young children with disabilities have been well included in planning, but how family-centered are those plans? This workshop invites participants to explore philosophy, consider real cases and practice strategies to meet the needs of the whole family.

T17 Implementing I.D.E.A. Following Reauthorization: Implications for Students, Families, and Schools

Kathy Boundy, Eileen Ordover, Frank Laski, Tom Gilhool, Judy Gran

The Individuals with Disabilities Education Act (IDEA) is a 22 year old civil rights law that ensures a free and appropriate public education for all children. In 1997, the 105th Congress voted to make significant changes to the law. Join several of TASH's legal experts as they discuss the significance of the changes, the current status of the new law, and specific strategies for ensuring adequate implementation and enforcement.

T18 Supporting Students with Autism/ PDD in Regular Classrooms

Barbara Cutler, Barbara Domingue, Herbert Lovett

This session will offer an understanding of Autism/ PDD and the implications for practical strategies and supports for students in regular classrooms.

T19 Grassroots Advocacy

Michael Auberger. Join Mike, TASH Board member and the founder of ADAPT, the group that defined "in your face" advocacy, to discuss strategies for moving systems without compromise.

TC – TASH Chapter Leadership and Development Day

This free session is offered to TASH Chapter Officers, chapter members, and people interested in forming a TASH Chapter. An interactive day is planned on chapter organization, administration, fundraising, membership drives, grassroots organizing and legislative action. You must register in advance. Lunch will be provided, and attendees will receive 25% off regular conference registration.

BEST COPY AVAILABLE

TASH Conference Registration Form

"We the People, *ALL* the People"

Sheraton Boston, December 10 - 13, 1997

Mail form to: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204-5201
Fax form to: TASH, (410) 828-6706.TDD (410) 828-1306 • Questions? Call 1-800-482-TASH
The registration application can also be found at http://www.tash.org

Registration Discounts

10% Discount for groups of 5 or more registering together (must be mailed and received in the same envelope)

50% discount off the rate that applies (for each person) for a regular education teacher registering with a special education teacher, a paraprofessional, or related services personnel, or for any support staff person registering with a self-advocate (must be mailed and received in the same envelope)

*Only one discount per registration.

You may use this form to register for the conference only, to register for the conference and become a TASH Member or renew your membership at the same time, or to [illegible] member only.

Please Print

Last Name ______________________ First Name ______________________

Preferred Badge Name ______________________

Agency/School/University ______________________

Mailing Address ______________________

City/State/Province ______________ Zip/Postal Code __________ Country ______________

Billing Address ______________________

City/State/Province ______________ Zip/Postal Code __________ Country ______________

Daytime Telephone ______________ FAX ______________

E-mail ______________________

Please enter the code off the brochure mailing label (if applicable) ________

Please Circle the Appropriate Number(s)

1 University/College Educator
2 Special Education Teacher
3 Professional Development
4 College Student
5 OT/PT
6 Legal Advocate
7 Regular Education Teacher
8 Administrator
9 Social Worker
10 Speech/Language Pathologist
11 Family Member/Parent
12 Self-Advocate
13 Support Services Provider
14 Government Personnel
15 Supported Employment
16 Psychologist
17 Early Childhood
18 Other

Please fill out this section only if you are registering for the conference:

TASH Membership: ☐ Individual ☐ Agency Membership #______________

(please note: up to three persons can register at the membership rate using an agency membership)

Student ID# (if applicable) __________ ______________

- ☐ I am becoming a member now
- ☐ I am renewing my membership now
- ☐ Please check here if you are a TASH Lifetime Member with Conference Privileges
- ☐ Please check here if the address above is a new address

Optional Service Information Requested (please request by November 1)

- ☐ Accessibility Details
- ☐ Sign Language Interpretor
- ☐ CEU Credits
- ☐ Child Care/Youth Activities (Note: you must fill out an application in advance to register. Space is limited)
- ☐ Roommate Referral Program
- ☐ List any accommodation needs

To Become a TASH Member or renew your Membership NOW. . .

You may also use this form to become a member at the same time you register for the TASH conference! This allows you to register for the conference at the reduced TASH member rate (see other side for member registration rates) or, *use this form to join as a member without registering for the conference.*

Membership rates are listed below. Determine the appropriate membership category, be sure to fill in the applicable rate on the reverse side of this form when entering payment information, and include payment at the time you submit your conference registration payment.

General International Membership (individuals)	$85.00
Agency/Business/University International Membership	$190.00
Self-Advocate, Parent ,Full -Time Student, Direct Support Worker, Paraprofessional, Personal Attendant, International Membership	$45.00
Family International Membership (2 people)	$130.00
Lifetime International Membership	$1,000.00

(Add $15.00 to memberships outside of the U.S. and Canada to cover additional postage costs)

Fill in appropriate membership rate on Line 4 on reverse side of this form.

TASH CONFERENCE REGISTRATION FORM

1997 TASH CONFERENCE - "WE THE PEOPLE, ALL THE PEOPLE" - DECEMBER 10-13

Registration Rates 1997 Conference	Current or Joining International Member	Non-Member	Please Enter Applicable Cost
General	$169	$289	
Student/Paraprofessional/Parent (Professional)	$135	$229	
Family (2 People)	$204	$420	
Self Advocate/Parent (non-professional)	$ 29	$ 39	
One Day Only ☐ Thurs or ☐ Fri	$ 99	$129	
Saturday Only Special	$ 70	$ 85	

1. Cost for Conference Registration from above .... 1. ________

- Less 10% for Group Discount or 50% for other discounts .... ________
- Please enter if applicable, see other side for details **(only one discount can be applied)**

2. Total Conference Registration Rate (Subtract discounts from line 1) .... 2. ________

Rates to add a Pre-conference Full Day TASH Tech Workshop (see descriptions, pgs. 8-9)

TASH Members	$65.00	NOTE: There is no charge for the Chapter Leadership Tash Tech.
Non-Members	$75.00	
Self advocate/Parent	$40.00	

1st Choice Tech # ______
2nd Choice Tech # ______

3. Add Cost of TASH Tech if applicable .... 3. ________

4. TASH Membership Dues Enclosed (If renewing or joining with this application, add applicable rate from other side) ..... 4. ________

5. To Also Join Your State Chapter Add $15.00 .... 5. ________
(only applicable if joining or renewing TASH international membership now)

6. ☐ Yes, I will donate $5.00 to support a self-advocate to attend the conference .... 6. ________

Grand Total Enclosed (add applicable costs for lines 2-6) ________

Payment Terms

Registration will not be accepted without payment by check, official purchase order, or credit card authorization. Please note that payment must be in U.S. Funds only. A $25.00 processing fee will be deducted from cancellations received before November 15, 1997, and added to purchase orders not paid within 30 days after the conference. No refunds will be given for cancellations after November 15, 1997. After that date, registrations will be on-site only and a $35.00 processing fee will be added to all registrations. A $15.00 fee for returned checks or unauthorized charges will be assessed.

Check enclosed   Purchase Order/State Voucher No. ______________________

Visa   Mastercard   Discover   Card Number ______________________ Exp Date __________

Signature ______________________________________

Integrated Resources Institute

a nonprofit corporation

Pizza Hut JOBS PLUS™

A Corporate Initiative to employ 2,500

Pizza Hut Job Plus™ has announced a national goal to employ 2,500 persons with disabilities by 12/31/97. Pizza Hut is specifically interested in recruiting individuals registered with their state vocational rehabilitation agency and or SSI/SSDI recipients.

Integrated Resources Institute (IRI) a non-profit Corporation, has been assisting Pizza Hut with its national employment initiative Jobs Plus™ since 1984.

IRI will facilitate your efforts to determine openings and arrange for interviews at local Pizza Hut corporate owned units.

To access IRI's free job development assistance, contact us toll free at (800) 704-5293, M-F 8:30 a.m. - 4:30 p.m. Pacific Coast Time.

IRI is prepared to assist your job placement efforts with Pizza Hut in a number of ways:

- **A listing of all corporate Pizza Hut units, address and phone numbers.**
- **A proven phone contact script for store manager contact.**
- **Interview preparation strategies.**
- **Regional Pizza Hut recruiter contacts to provide additional support.**
- **Provide whatever assistance required to help you obtain employment for your Vocational Rehabilitation or SSI consumers.**

IRI looks forward to working with you
on this unique employment initiative.

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Executive Board

Frank Laski, *President*
Mark Partin, *Vice President*
Liz Healey, *Chair of the Executive Committee*
Dianne Ferguson, *Secretary*
Mike Auberger, *Treasurer*
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MEMBERSHIP INFORMATION

Referred by:

Name: ____________________

Address: ____________________

City/State/Zip: ____________________

Telephone: (   ) ______________   Fax: (   ) ______________

Please Check Appropriate Categories
(not more than three):

( ) Administrator
( ) Adult Service Provider
( ) Case Manager
( ) Day Personnel
( ) Early Childhood Services
( ) Educator (University/College)
( ) Early Intervention Specialist
( ) Friend
( ) Gov. Personnel (Federal, State, Local)
( ) Higher Education
( ) Human Services Provider
( ) Interested Individual/Advocate
( ) Legal Administrator
( ) Library
( ) Occupational/Physical Therapist
( ) Paraprofessional/Direct Care
( ) Parent/Family Member
( ) Primary Care Provider
( ) Personal Assistant
( ) Professional Advocate
( ) Psychologist
( ) Regular Education
( ) Residential Services
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Student (College/University)
( ) Support or Related Services
( ) Supported Employment Personnel
( ) Teacher (Direct Service)
( ) Teacher Trainer
( ) Vocational Services
( ) Other

General Membership (individual) ...... $85.
Agency/business/university/college/library/school .... $190.
(allows 3 conference attendees at the member rate)
Self Advocate, Parent, Full Time Student, Direct Careworker/Paraprofessional/Personal Attendant (for whom payment of full fee would present a hardship) .... $45.
Family (group rate) .... $130.
Lifetime Member .... $1000.

All dues are $15 higher for members outside the U.S. & Canada. Funds must be submitted in U.S. Dollars.

If you would like to charge your membership, please fill in the necessary information:
( ) Mastercard ( ) Visa ( ) Discover

Card Number ____________________

Expiration Date ____________________

Signature ____________________

( ) I would like to arrange to spread my payments out.
Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

How did you learn of TASH: ____________________

What, in particular, inspired you to join: ____________________

What other disability organization do you belong to: ____________________

If you are applying for a student membership, please provide the following information:

Department ____________________

College/University ____________________

Student I.D. Number ____________________

Anticipated year of completion ____________________

( ) Please check here if you would like us to send information about your local TASH Chapter.

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Address Correction Requested

OCTOBER 1997